**The *Dys*-Appearing Body: Understanding the Everyday Lived Experience of Women with
Fibromyalgia.**

by

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Abstract

This thesis explores the meaning of the everyday lived experience of women with Fibromyalgia (FM), a chronic musculoskeletal pain syndrome, in Ottawa, Ontario. In particular it explores how individuals verbally and non-verbally communicate about their embodied experience of living with an invisible chronic illness of uncertain biomedical etiology. The adoption of a phenomenological perspective guiding this research enables one to resituate the experience of illness within the complete life of suffering individuals where the lived experience of FM emerges as an altered yet nonetheless complete mode of existence. Further, this thesis argues that the cultural conceptions of FM, the outward invisibility of this syndrome and the inherent difficulty in communicating about pain coincide to inform the primary mode of communication of experience of FM through a subtle withdrawal from previously meaningful activities and relations in the lives of sufferers.

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Introduction

Sitting in a rocking chair in a cozy living room warmed by the mid-afternoon sun opposite a woman named Eliza I was struck by her summation of the complexity surrounding Fibromyalgia (FM), a chronic musculoskeletal pain syndrome, which she has lived with for twenty-nine years: "...It's been a really long road. It's almost science fiction when you think of all the different things you can have with it." (Interview December 2011). She was originally diagnosed in the early 1980's when FM was known as Fibrositis¹ and there was little existent literature on this nebulous disorder, which she was told was a malady of housewives that would most likely pass by the time she was in her mid-fifties; a foretelling that did not come true. Now in her early seventies Eliza's illness narrative is replete with cautionary tales of medical encounters, an acuity of knowledge of the body, and an amazing resilience to appreciate what life has to offer; all underscored by a continual striving to this day to understand her illness experience. While her story is in and of itself unique what it discloses is the confluence of recurrent ambiguity surrounding FM at both the clinical and thus societal level as well as the episodic pattern of FM, which requires a constant search for meaning to and alleviation of a diversity of symptoms in addition to the pronounced pain and fatigue characteristic of this syndrome.

The experience of pain has been described in academic literature as the ultimate private sensation, which submits individuals to the vital rhythms of their body thus initiating a disjuncture both within the embodied self and between self and others as the taken-for-grantedness of the body in health disappears (Leder 1990, Jackson 1994). Further, the intrinsic

¹ Fibrositis is the outdated term for Fibromyalgia which was discontinued in clinical practice as it implies the presence of inflammation in either bodily tissues or nerves which is not usually present in FM. (Clauw and Wallace 2009:89)

aversiveness of pain characteristically challenges the mutual intelligibility of the world and demands the reorientation of one's life toward an interpretation for and understanding of their illness (Good 1994). This latter point is clearly evident in Eliza's reference to FM being akin to an object drawn from science fiction and thus often beyond immediate intelligibility. The phenomenological reorientation of these individuals local moral worlds (Kleinman 1994) is thus inherently either facilitated or impeded by social structures and systems of knowledge of which biomedicine is paramount (Good 1994) as it is our primary mode of knowing the body in Western culture.

Further, while there is a well developed body of literature on the clinical aspects of various chronic illnesses there remains a paucity of information on how individuals live with chronic illnesses and seek healing and restored well-being beyond the clinical context (Risor 2010:134). The necessity of exploring and understanding the everyday lived experience of illness has emerged with the growing recognition that the reductionist categories of "healthy" or "sick" obfuscate the complex experience of individuals with chronic illnesses. The rising rates of chronic illness signify what Frank (1997) has termed the emergence of a remission society; for individuals living with these illnesses exist in an altered state of being that is neither absolutely healthy nor generally, acutely ill. Mary, another participant in this research clearly speaks to this notion as follows:

...I'm not sick. I do have an illness or disorder or whatever it is; but I'm not unwell, but I'm not well either. I think that we do a lot of times have trouble dealing with people who don't fit nicely into one category or other. I'm sort of in that liminal space that's uncomfortable for people to think about. I'm that, you know... that sort of uncategorizable commodity and that's the problem really with Fibromyalgia. There is no official test to put you into that category. (Interview January 2012)

Therefore, in the vein of understanding the nuanced experience of individuals with chronic pain the research for this M.A. thesis focuses on exploring the everyday lived experience of women with Fibromyalgia (FM), a contested chronic musculoskeletal pain syndrome of ambiguous etiology. The contestation surrounding FM arises from its twofold invisibility; on the one hand you have individuals who for the most part appear perfectly healthy despite profound levels of pain and fatigue amongst a plethora of other symptoms, and; while on the other hand one finds a diverse set of disruptive corporeal symptoms with no known biomedical cause as there is no definitive positive diagnostic test for organic pathology in FM. Fibromyalgia therefore inherently poses a challenge to the underlying Western tenet of “seeing is believing” and as Mary-Ann, a woman who participated in this research, ruefully confirms: “...You know, if you only have a hammer, everything needs a nail.” (Interview December 2011).

While there remains considerable debate over the legitimacy of FM as a biomedical syndrome (to be elaborated later on) this thesis does not seek to explicitly engage that debate but rather is poised to explore the phenomenological perspective of individuals who live with this illness. On the broadest level this research was undertaken with the goal of gaining insight into how cultural processes of constructing knowledge of health and illness are constituted in and are altered by individual experience and performance. Chronic pain conditions generally, and FM specifically, present an interesting avenue through which to approach this research goal as they recurrently evade clinical explanations and are notoriously difficult to communicate about. However, a phenomenological approach can address such symptoms that often “reveal the fault lines of society” (Kleinman et al. 1994:3). The pragmatic goal of this research was therefore to gain an understanding of how individuals living with FM communicate about the meaningful experience of living with this contested illness, which challenges the discrete dichotomy of either

somatic or psychological causality of disease. This thesis will thus contribute to the growing body of literature within medical anthropology concerning chronic illnesses and disability and more specifically to the literature that addresses chronic pain. Furthermore, through focusing on the embodied experience of FM as it is lived in the everyday world this thesis seeks to take a step, metaphorically speaking, toward redressing the current over-emphasis in the existent literature on the quantitative, biomedical aspects of Fibromyalgia.

In the early weeks of September 2011 I began the fieldwork portion of this research here in Ottawa, Ontario and quickly learned about the disjuncture between proposed research and research as it pans out in the field. The ambiguous status of FM within biomedicine translates into a parallel perception of disbelief in society in general wherein social support for this illness in terms of local programs and social outreach is diffuse at best and is commonly organized on a volunteer basis by individuals who themselves live with FM. Thus when I initially contacted local Fibromyalgia support groups I was confronted with the reality that three of the four groups were no longer active due to various health and financial constraints on the part of the organizers. The organizers of the remaining FM support group consulted their members and quite fortunately consented to my participation in their monthly meetings starting in October. A portion of this research therefore took place at those monthly meetings held in a local community facility in Ottawa from October 2011 through to March 2012. The predominant focus of the support group meetings was to provide an arena for individuals to voice their experience of living with FM and thereby gain a communal validation for their experience while sharing knowledge of FM related therapies and treatments in what I would consider a positive and empowering manner (to be further discussed in chapter five). At the end of the first support group meeting I attended I was explicitly asked by the group what my impressions of them were,

as they are indeed acutely aware of the common societal perception that individuals living with FM are malingerers, naggers and fakers who are out to take advantage of both the medical and disability system. My unplanned response, as both an anthropologist and an individual with limited personal experience of FM, was that I quite honestly hadn't known what to expect and additionally, while I was aware of these cultural pre-conceptions I had personally committed to keeping an open mind. Further, through pre-emptively addressing these stereotypes in our first meeting these women authoritatively asserted their embodied knowledge of FM to discursively disrupt any normative image of individuals with FM that an outsider such as myself might harbour.

I had originally anticipated completing the participant observation portion of the research through one local support group and recruiting participants for the interview portion from the other support groups or through general practitioners offices, both of which were ultimately unfeasible. The nine women I interviewed concerning their experience of living with FM thus were members of the support group whose meetings I attended for five months. Due to the sometimes immense planning required to leave one's house (to be discussed in chapter four) the majority of the nine interviews were conducted in the homes of the participants and ranged from forty-five minutes to two and half hours long. In addition, the interviews were semi-structured according to a pre-determined set of questions although the overall goal of the interview was to enable these women the conditions to voice their experience of living with FM.

Finally, I had the opportunity to attend the Second Biennial International Chronic Fatigue/Myalgic Encephalomyelitis (CFS/ME) Conference here in Ottawa from September 22nd to 25th 2011. This event was a clinical conference on current biomedical research concerning not only CFS/ME but also Fibromyalgia (FM) and Multiple Chemical Sensitivities(MCS) that was

open to both clinical practitioners, researchers and individuals living with any of the three above illnesses (to be discussed in chapter one).

I acknowledge that because of time constraints and the difficulty in identifying and establishing contact with a group of individuals who live with an invisible chronic illness, the sample from which I am drawing my conclusions of the lived experience of FM is small. In addition, the choice to solely interview women for this research was informed by existent statistics and literature on this syndrome which assert that it predominantly affects women. Further, as the participants are all members of a local support group, despite considerable individual divergence in illness experience, they represent a group of individuals with similar approaches to managing FM that may potentially not be entirely representative of the broader experiences of living with Fibromyalgia. Thus I feel it is incumbent upon me to explicitly state that the over-arching themes discussed through-out this thesis are representative of the shared, emergent themes of the particular, situated illness narratives of FM told by the participants in this research.

The focus of Chapter One is on providing an overview of the clinical history of Fibromyalgia as well as an introduction to the anthropological literature on chronic pain conditions in general, as there is currently a lack of studies specifically focused on FM. Further, there will be a brief discussion of the emergence of research focusing on the lived experience of illness as a necessary counterbalance to the clinical emphasis on symptoms which obscures the complexity of life with a chronic illness.

Chapter Two will elaborate on the phenomenological consideration of the body in health and illness, as it is the theoretical framework which informs this research. The chapter will first

provide an understanding of what has been called “the ecstatic mode of being-in-the-world” (Leder 1990). This mode, which is characterized by a productive unawareness of the functioning of one’s own body, provides the phenomenological basis of common everyday experience. A fundamental change can then be seen to occur in illness as one’s whole being is forcibly reoriented to what Leder (1990) calls a “recessive mode of existence”. Further, the underlying metaphorical nature of our conceptual system will be briefly discussed as the experiential basis of metaphors enable us to comprehend unfamiliar experiences in creative ways, which is of particular salience for chronic pain and FM.

The remaining chapters in this thesis provide the ethnographic data of the lived experience of women with FM who participated in this research. Chapter Three will explore the initial stages of illness manifested as a disruption in intentionality in these women’s professional lives that was broadly represented in this research as the experience of Falling Apart. The topics discussed in this chapter address the difficulty in maintaining employment as these women experience the onset of FM, struggle to ignore their diverse and problematic symptoms and ultimately, after receiving a diagnosis are confronted with a loss of professional identity compounded by the often stigmatizing label of “being a Fibromyalgic”.

Chapter Four focuses on these women’s everyday life with FM as they learn to live with this illness through adopting an approach to daily activities and relations referred to as “pacing themselves”. The phenomenological theme of spatio-temporal constriction characteristic of illness is brought out through discussing their withdrawal from social activities, made urgent by the necessity to listen to and understand their bodies which ultimately leads to a revaluation of life priorities and goals.

Chapter Five discusses the search for a meaning to, and understanding of, the illness experience commonly expressed by the women in this research as “a journey” or “a long road” and academically referred to as the “hermeneutic search”. The contents of this chapter focus on the conferring of a diagnosis of FM as the initiation of this “search” that is continuously perpetuated through self-education, a combination of allopathic and alternative therapies and for the majority of these women, knowledge sharing via participation in the local FM support group.

Finally, as an aside, in addition to being asked about my perceptions of FM, I was also asked at the first support group meeting I attended, the clinical conference and subsequently in each of the nine interviews I conducted, to explain why an anthropologist would be interested in studying FM and what role anthropology occupies beyond the halls of academia within the context of health and illness. It is my hope that through reading the following pages of this thesis the answer to the question of why anthropology would study FM becomes obvious: as illness is inseparable from life it is a ripe area of cultural analysis. The last question is a bit more difficult to respond to as the answer is one which I hope to better understand myself as I progress in my studies of anthropology, although I will propose a response from my current perspective in the conclusion to this thesis.

Chapter One: An Introduction to Fibromyalgia

The fact that the very word “pain” has its etymological home in ‘poena’ or ‘punishment’ reminds us that even the elementary act of naming this most interior of events entails an immediate mental somersault out of the body into the external social circumstances that can be pictured as having caused the hurt (Scarry 1985:16).

As suggested by the above quote, pain generally and Fibromyalgia, as a form of chronic pain specifically, presents an expansive avenue of exploration as it intrinsically constitutes a subjective experience that initiates a confrontation with the precariousness of one’s own corporeal unity. To date, the difficulty in adequately defining pain persists although the significance of pain as an allegory for human suffering is well established (Kleinman 1989). It has been said that it is not simply the manner of bearing one’s pain that is most important to those who suffer but that one’s pain be collectively understood and thereby imbued with meaning (Buytendijk 1962). The remainder of this chapter will thus elaborate on the overarching cultural systems that inform both our understanding of FM and ultimately the particular meaning ascribed to this illness. The discussion will turn first to a consideration of the history of Fibromyalgia from a biomedical perspective before progressing to a critique of the materiality of biomedicine, which ignores the embodied experience of FM. This nescience highlights the necessity of an anthropological approach studying the lived experience of FM.

Fibromyalgia as a Biomedical Syndrome Defined

The technical, biomedical definition of Fibromyalgia is that of a “central sensitivity syndrome characterized by increased responsiveness to sensory afferent stimuli, which results in pain amplification” (Clauw and Wallace 2009:19). What this technical definition conveys is the

notion that FM is a form of chronic widespread pain that falls under the category of an idiopathic², or central, pain syndrome with no detectable pathology or inflammation of either bodily tissues or nerves. Alternatively, the most common everyday description of Fibromyalgia (FM) is that of a chronic widespread musculoskeletal pain syndrome of unknown cause that is predominantly diagnosed in women. Further, to clarify, the term syndrome in biomedical nomenclature refers to a construct for a poorly understood condition that is not considered a discrete disease.

The over-arching guidelines for diagnosing FM were agreed upon in 1990 by the American College of Rheumatology and include the following criteria; the presence of widespread pain in all four quadrants of the body and axial skeleton accompanied by tenderness in at least eleven of eighteen identified trigger/tender points with the application of four kilograms of pressure upon manual palpitation, that persists for at least three months of duration without any alternative identifiable etiology (Clauw and Wallace 2009:6).

While this set of criteria remain the formal delineation of symptoms for FM, individuals who fit this profile tend to characteristically have a history of other regional syndromes broadly classified as central sensitivity syndromes. This sweeping rubric of central sensitivity syndromes include such diverse conditions as; gastrointestinal syndromes, urological disorders, gynecological syndromes, psychiatric conditions, chronic fatigue/myalgic encephalomyelitis (CFS/ME) and multiple chemical sensitivities (MCS) (Clauw and Wallace 2009:10). Despite consensus that the 1990 criteria remain the standard for diagnosis there is significant debate within the biomedical community over the validity of trigger/tender points as a definitive aspect

² Idiopathic here refers to pain which is centralized in the body and is without known cause (Clauw and Wallace 2009)

of the diagnostic process for FM. This contestation was a recurrent theme at the Second Biennial International Chronic Fatigue/Myalgic Encephalomyelitis (IACFS/ME) Conference in Ottawa that I attended in September 2011. The issue raised was the propensity in clinical practice to favor trigger/tender points over the other diagnostic markers, all somewhat vague as described above, which potentially leads to a devaluation of the importance of other symptoms for individuals and the perpetuation of primary care physicians under-diagnosing FM.

The recently published results of the 2010 Canadian Community Health Survey (CCHS) indicate that there are currently an estimated 439,000 individuals diagnosed solely with FM in the country (National ME/FM Action Network 2011:3). However, the impossibility of absolutely distinguishing this syndrome from CFS/ME³ and MCS⁴ is reflected in the conglomerated estimation that 1,415,000 Canadians are living with two or more of these conditions (National ME/FM Action Network 2011:4). The anticipated biomedical trajectory of diagnosis via verifiable organic pathology followed by a regimented, curative treatment regime is unavailable to individuals experiencing symptoms that correlate with the clinical profile of FM. The ascription of the label of FM therefore often comes out of the confluence of medically unexplained symptoms (MUPS) and a lengthy series of negative diagnostic tests ruling out various other diseases (Park and Knudson 2007, Rosenzweig and Thomas 2009). As one woman, Mary, who participated in the research summarized: "I've been tested for everything from Lyme disease to HIV to I don't even know what. So it's definitely Fibromyalgia" (Interview January 2012).

³ CFS is defined as "unexplained fatigue lasting more than 6 months associated with musculoskeletal and systemic symptoms. Most CFS patients fulfill the criteria for Fibromyalgia." (Clauw and Wallace 2009:88)

⁴ MCS is defined as a "controversial condition suggesting that chemicals in the environment produce symptoms and signs at levels not thought to be harmful." (Clauw and Wallace 2009:91)

Additionally, the typical age composition of the population diagnosed with FM reveals that it is a syndrome that primarily affects individuals of a working age with fifty percent of individuals falling in the 45-64 age cohort and another twenty-five percent falling in the 25-44 years of age cohort (National ME/FM Action Network 2011:4); a statistic confirmed by the participants of this research whose age at diagnosis ranged from early 30's to mid 50's. Along with the concentration of the incidence of FM in individuals of a working age, FM has been typified as a syndrome that predominantly affects women with seventy-nine percent of those living with it being female, the highest rate of female incidence of any chronic illness surveyed in the 2010 CCHS (National ME/FM Action Network 2011).

In addition, due to the recurrent ambiguity in etiology of FM and the staggering array of symptoms and co-morbid syndromes associated with it, the administering of appropriate treatment remains a process of trial and error. An excerpt drawn from *Fibromyalgia: The Essential Clinician's Guide* asserts that:

There is no single measure, metric, or index that allows a treating practitioner to assess, in a reliable, efficient manner, how a fibromyalgia patient is responding to a therapeutic intervention (Clauw and Wallace 2009:55).

Further, the combination of pharmacological and non-pharmacological therapies is frequently espoused for the optimal management of FM, an approach which requires a significant investment of time and resources on the part of not only the individual but the primary physician as well. The most common non-pharmacological methods endorsed by practitioners for individuals with FM are exercise programs, cognitive-behaviour therapy and patient education programs (Rosenzweig and Thomas 2009:235). The debilitating nature of the condition is reflected in the common finding that individuals living with FM have consistently reported lower

perceived physical and mental well-being as well as a high rate of dependency on others to assist in performing the activities of daily living (Park and Knudson 2007, Rosenzweig and Thomas 2009). In addition, the recurrent clinical ambiguity surrounding the status of FM and the absence of definitive management strategies is well reflected in the results of the 2010 CCHS wherein FM ranked as the primary unsupported chronic condition in Canada with thirty-one percent of respondents self-reporting unmet healthcare and daily needs (National ME/FM Action Network 2011:6). This statistic supersedes the rates of unmet healthcare needs for such prolific chronic conditions as arthritis at seventeen percent, cancer at sixteen percent and Alzheimer's disease and other dementias at fourteen percent- all illnesses which are disproportionately reflected due to the exponential growth in the elderly age cohort in Canada(National ME/FM Action Network 2011:6) highlighting a need to understand the everyday concerns of living with FM.

Thus, the over-arching indications of the statistics drawn from the 2010 CCHS concomitant with the ambiguous clinical profile of this condition present an incomplete and limited picture of FM that points to the necessity of an alternative,- anthropological in this case-, approach to understanding this syndrome. When speaking of why FM remains such a poorly understood condition, both within the biomedical community as well as in society at large Karen, a participant in this research in her mid-fifties, provided an interesting summation of her personal experience in light of a radio program she had recently heard:

Back in the seventeen hundreds he said something about you would go to the doctor and say, "I'm sick, I don't feel well" and the doctor would then start asking you a bunch of questions. Now if you go to the doctor it's not that *you* say you're sick it's *the doctor* that *decides* you're sick after he's done a bunch of tests. And he'll say, "Oh your blood work shows blah, blah, you're sick." But if he does all these tests and can't find anything, then the doctor thinks, "Oh you're not sick, we can't find anything wrong with you," as opposed to you being the patient. So I mean that's why. Doctors are so used to having to find, having some test, for something to find

you with disease x and if they can't then they don't know how to deal with it. And you combine that with the fact that time is so short in an office and they don't want things that they have to investigate because they only get paid per visit, so after ten minutes you're gone. So I mean I also feel sorry for them in the sense that the system isn't geared for people whose illnesses require longer appointments or regular treatment. (Interview December 2011)

Karen's introspection provides a poignant commentary on the confluence of technical, biomedical knowledge and the larger, cultural ideals and norms of the moment. In this instance individual experience of an illness provides a potentially ripe area of inquiry for understanding the inseparability of these two systems of knowledge. While there remains a paucity of information specific to Fibromyalgia within anthropological literature there is a well-developed body of studies exploring illness generally and chronic pain specifically from alternative perspectives, which is also applicable to research concerning FM.

A Critique of the Materialistic Approach to Understanding Illness

In order to assert the primacy of the pathological fact the clinician is prompted to abstract the patient from the process, meaning the patient as a unity becomes bracketed from the physiological dysfunction or disease to be diagnosed and treated (Foucault 2003[1973]:7). This process is clearly evident in the above excerpt where Karen speaks of the shift in power of who confers the label of being sick. The implications for a biomedical approach to chronic pain are profound; where there is no existing underlying organic pathology the normative trajectory of the biomedical regime is truncated and the clinician is confronted not with a discrete, partitioned entity but the patient in their complex and confusing entirety. Kleinman has aptly summarized this as follows:

Chronic pain patients are the *bête noire* of many health professionals, who come to find them excessively demanding, hostile and under-mining of care (1989:57).

Further, the language employed in the biomedical encounter has been described as a rich cultural language in and of itself that expresses a technical perspective of reality and encodes a certain set of social relations inherent with power dynamics. The role of biomedicine, as a dominant form of cultural knowledge of the body in Western society, thus ultimately serves to conjoin broader moral concerns with technical expertise (Good 1994:5).

It has been posited that biomedicine has been imbued with the cognitive and social authority to describe bodies on two practical levels, to the individual consulting a practitioner as well as to the larger society (Wendell 1996:117). Thus in the face of a life disrupted by the onset of illness and/or pain there is a cultural propensity to turn to biomedicine not only for the treatment of symptoms but for a restoration of coherency in one's life. Underlying the impartial observer stance of biomedicine, however, is the core conceptualization of the body not as an embodied being, but as a material object. This notion of the body as a purely physical object is attributable to the epistemological legacy of the split between the body and mind underscored by Descartes' assertion of the primacy of the technical practice of dissection as the origin of scientific knowledge of the body (Leder 1990:145). This notion has been critiqued as fostering a purely materialistic perspective that obfuscates the lived reality of individual's in sickness. As Leder asserts; "The patient's own experience and subjective voice become inessential to the medical encounter" (1990:147). The cultural credence ascribed to this one form of knowledge thus entails a potential for the delegitimation of personal experience as the reliance on third person accounts of individual's bodies in terms of discrete conditions typically supersedes the personal phenomenological accounting of illness (Wendell 1996:119). Anthropological inquiry

into the experience of illness consequently has stressed the necessity of complementing a purely biomedical perspective best expressed through the following statement: “Disease occurs of course, not in the body, but in life” (Good 1994: 133). Anthropological studies of pain have therefore focused on understanding how the social structures and practices can either mediate or further erode what Scarry has so poignantly termed is at stake, in her work on pain and torture, as the making and unmaking of the world (1985).

The Necessity of an Anthropological Approach to FM

Pain has been widely recognized as a pervasive element of human existence that paradoxically challenges the mutual intelligibility of the world that we live in as it is oft coined as the ultimate private experience (Kleinman et al. 1994:1). The embodied nature of human life, a conception emergent in medical anthropology in the past three decades, suggests that one re-conceptualize pain not simply as a corporeal sensation but rather as a total experience reflective of the larger dialectic between personal and cultural (Jackson 2001). Thus the experience of pain as an anthropological area of inquiry emerged as yet another lens through which to understand the inter-relation of the biological and the cultural in the constitution of the categories of health and illness. While acute pain, usually of sudden onset, short duration and with visual cues of causality, is often endowed with a culturally delineated set of behaviors on the part of sufferers and non-sufferers alike chronic pain evades this patterning (Helman 2007: 194). The intrinsic invisibility of chronic pain challenges not only social conceptions of illness causality but the over-arching system of knowledge of the body that Western culture is reliant upon, namely biomedicine. Chronic pain conditions, such as FM, have therefore been described as disclosing:

"the fault lines of society" (Kleinman et al. 1994:3) due to the persistent precariousness of their status as not quite legitimate diseases, or syndromes, as discussed above. For conditions such as FM the biomedical stance tends to perpetuate the notion that they are non-sensical thereby compounding the societal view that individuals suffering from said conditions are malingerers. The oft reported role of a biomedical diagnosis reincorporating individuals into society becomes unavailable to persons with FM as the diagnosis confers a label for a syndrome that is widely believed to be psychosomatic, thus implying that it is unreal.

In addition, social science investigation into chronic illnesses has focused on the structure and inherent power dynamics underlying the clinical encounter which simultaneously informs and constrains both the manner and type of information that an individual discloses to their physician (Wendell 1996:133). Jackson, in her ethnography of a chronic pain clinic, reveals that the emotional aspect of pain tends to be downplayed due to the pervasive and negative association of emotion with irrationality and psychosis in Western culture, thereby indicating that the discursive expression of pain is indeed culturally informed (1994:209). Pain can therefore be considered as being permeated with meaning and shaped by culture (Jackson 1994:210). In the West this cultural patterning of pain behaviour entails the adoption of the morally espoused attitude of the "stiff upper lip", meaning to bear one's pain stoically (2001:145). Further, exploration of the communication of pain in Jackson's work posits that individuals report a sense of failure when speaking of their pain-filled experience subtly reiterating Scarry's assertion that "physical pain destroys language" (1985:19). The centrality of pain to both the individual's experience and attempted expression stems from the inherent aversiveness of pain which submits individual's to the vital rhythms of their bodies (Good 1994).

In addition, the anthropological literature on chronic pain strongly asserts that it inherently challenges not only an individual's place in their larger social network of friends and co-workers, but even the most intimate of family relations. As a result, the private world of individuals in pain loses its relations to others initiating a search for an understanding of and thereby a meaning for their experience which typically takes the form of the construction of an illness biography or narrative (Good 1994). The narration of illness experience emerges as a means through which to reclaim a coherency to a disrupted life by authoring their unique sequences of events that relate to health, illness and wellbeing (Manderson 2011:38). The exploration of chronic illness generally, and chronic pain particularly, from an anthropological perspective thus enables one to transcend the purely physical accounting of disease and inquire into the meaning of the experience of ill health which is necessarily historically and culturally situated. As Jackson has so aptly asserted: "Pain always has meaning; even the oft-remarked meaninglessness of chronic pain is meaningful" (2001:144)

The exposition of a brief history of Fibromyalgia from two perspectives, both the biomedical and the anthropological, has been presented as a means of foregrounding the ambiguity at the heart of discerning the meaning of the experience of living with FM. The recurrent contestation surrounding FM, in conjunction with a strong history of anthropological studies highlighting the difficulty of achieving a collective understanding of one's pain suggests that now is an opportune moment for exploring individuals' phenomenological accounting of their illness.

Chapter Two: The Phenomenological Perspective of Health and Illness

The problem of pain, as that of death, belongs to our personal life and can only be solved within it's framework (Buytendijk 1962:28)

The implementation of phenomenology as a theoretical perspective guiding this research on Fibromyalgia takes its point of departure from the assertion of this philosophy's totality of one's being. This enables one to redress the purely physical accounting of illness predominant in the literature and instead explore the meaning of FM when resituated in the context of the lives of those experience it, as the above quote demands. The chapter will begin with an introduction to the phenomenological understanding of the body as elucidated in the work of Merleau-Ponty (Phenomenology of Perception [1945] 1962) and applied in the work of Drew Leder (1990), who elaborated a framework for considering the body in disease which is especially applicable to the exploration of FM. Through an initial discussion of the body as it is experienced in everyday life one will be better able to understand the fundamental alterations to one's existence that occurs in illness. Therefore, after establishing the theoretical understanding of the structure of bodily experience the remainder of the chapter will progress to a phenomenological consideration of the communication of one's lived experience, including a discussion of the experiential basis of metaphor theory as laid out by Lakoff and Johnson (1980). The importance of metaphors for a study of FM arise from their grounding in physical experience, which enables those who are ill to communicate their often misunderstood corporeal experience to others through either common cultural representations or their own unique expressions.

The Ecstatic Body: The Experience of Everyday Life

To understand how one's body becomes juxtaposed to one's sense of self in the experience of pain the discussion will first focus on how one experiences the world in the absence of pain, in other words in well-being. Phenomenology asserts that sensory perception is the primary mode of experience thus the initial part of this section will provide a brief overview of this phenomenon as the basis from which we will build our understanding of the lived body. The act of perception is the immediate, pre-objective acknowledgement of the world that occurs via the senses we possess as human beings. Though we are at once comprised of a multiplicity of limbs, organs, and other biological structures there is an intrinsic unity to our corporeality, referred to as the bodily schema (Merleau-Ponty 2002 [1962]:113). Further, our given, upright posture as humans encodes a certain manner of being-in-the-world that orients our perceptual field such that there is a point-horizon or figure-ground structure to our perception (Straus 1952). Our upright orientation combined with the unity of our body schema entails that in the act of perceiving our corporeal functioning becomes relegated to the margins of perception. As Leder succinctly summarizes:

Physically, we act from a surface organ that itself is a lacuna in its actional field. In attentional terms, we ordinarily focus upon the goal of activity not on our corporeal means of accomplishment. Functionally, we rely upon a set of abilities we cannot fully thematize (1990:20).

It is precisely because our body remains on the periphery of our perception thus evading explicit exploration that it is the unacknowledged tertiary term in the point-horizon structure or the pivot around which all else rotates (Leder 1990). In other words, in what Leder terms the ecstatic mode of being-in-the-world one's focus is drawn from the body to the person or object they are engaged with. As such one's legs for example and other areas of the body recede to the

background when walking toward a certain destination and do not demand explicit attention; the body disappears from our awareness. The definition of the term disappearance in this process is that of “not-appearing” highlighting the un-thematized, supportive role of bodily regions in the ecstatic mode of being. This absence of our body complemented by the call that the world places on us means that our intentionality both in terms of motility and affective attitudes radiates outward. In terms of the relation between embodied self and world, the ecstatic mode of being is characterized by what Leder calls a from-to structure: “from” the body we are directed “to” the objects of our experience (1990:18). There is then at the heart of perception what can be thought of as an absence on the part of the body in the ecstatic mode being-in-the-world as we are not fully cognizant of the biological means with which we accomplish our intentions. Further, phenomenology holds that we intrinsically inhabit space and time and belong to them through our body which is our vehicle of being-in-the-world and our means of communication with the world. As Merleau-Ponty writes:

The space and time which I inhabit are always in their different ways indeterminate horizons which contain other points of view. The synthesis of time and space is a task that always has to be performed afresh (2002[1962]: 162).

The absence of the body in experience therefore includes a temporal dimension: in order to have a future in which to fulfill my intentions and a past from which to take my motivations, I need to live in a present which is not fully transparent to me. Being bodily “here” paradoxically means to be also elsewhere, with things and others.

The establishment of a sense of coherence to one’s experience in the world through the synthesis of both time and space is posited as being fundamentally accomplished by and through one’s working acts. The definition of working acts adopted from Schutz is as follows:

Working, then, is action in the outer world, based upon a project and characterized by the intention to bring about the projected state of affairs by bodily movements (1965: 212).

Through working acts we experience what has been termed standard time, which is the intersection and unification of spatialized, universal time and the inner time, or *durée*, where our experiences are linked to the past through memory and the future through anticipation (Schutz 1965: 215-216). In addition, our determinate, upright stance confers a certain ordering of perceptual experience from which “here” arises spatially a world of varying distances and “now” a temporally meaningful realm of past and future goals (Leder 1990:22). Thus the experienced distance is that which unfolds in the point-horizon structure between the experiencing individual and the other person, object or goal (Straus 1952: 546). Further, the world of everyday life is replete with assumptions of mutuality in experience that Schutz summarizes as follows:

I share this world and its objects with Others; with Others, I have ends and means in common; I work with them in manifold social acts and relationships, checking the Others and checked by them. And the world of working is the reality within which communication and the interplay of mutual motivation becomes effective (Schutz 1965: 227).

The working world while only one potential life-world amongst many is the primary world of everyday life and is characterized by an assumption of commonality in experience that is lost in illness (to be discussed later on). Additionally, Schutz holds that the working world is the fundamental domain in which the constitution of the self is accomplished:

Living in the vivid present in its ongoing working acts, directed toward the objects and objectives to be brought about, the working self experiences itself as the originator of the ongoing actions and, thus, as an undivided total self (1965: 216).

What the above quote highlights is the indeterminacy of being-in-the-world wherein the melding of personal into biological is accomplished anew at every instant and is manifested

through our outward intentionality. Further, the process of developing new skills and habits is characterized by their incorporation into one's repertoire of available uses of the body whereby they, too, disappear from explicit awareness (Leder 1990:32).

Thus, the ecstatic body is characterized by the dialectic of absence and presence revealing the shifting nature of the lived body which is in constant transformation through the acquisition of new skills and habits (Leder 1990:30). The affective call of the world, through which the embodied response is manifested in intentionality, demands a certain re-shaping of one's corporeal abilities over time. The underlying from-to structure of engaging in the world necessarily entails a reciprocal exchange where one's lived body is altered by the solicitations of the world and the world itself is altered by one's working acts. Thus the disappearance characteristic of the ecstatic body is said to expand to those areas of the world with which we are in intimate, continual contact (Leder 1990: 35). In other words, familiar items such as clothing and furniture, and even spaces such as rooms in a home, and one's own neighbourhood become extensions of our corporeality in a sense as they no longer capture our focal attention and thus recede from our explicit awareness as we engage in our daily activities and projects.

The Recessive, Dys-appearing Body: the Experience of Illness

The consideration to this point has been the ecstatic mode of being-in-the-world where we are centrifugally oriented away from our bodies and towards projects, goals and other people in the outer world. In contrast, the recessive mode of existence is a centripetal orientation characterized by the collapse of the body upon itself as it falls back from conscious control and perception (Leder 1990:69). At moments of corporeal dysfunction the absent body emerges to

our explicit awareness and appears as an “Other” juxtaposed to our concept of self (1990:70). Illness, pain particularly, overcomes the normal absence of the body in experience as certain areas of the body that were previously silent exhibit disruptive symptoms. Further, the temporal nature of pain characterized by changes not only in sensation but intensity, referred to by Leder as its episodic structure, seizes one’s attention and demands a re-orientation of one’s intentionality (1990:71). The normalcy of the from-to structure of engaging in the world is challenged as pain exerts a telic demand that disrupts one’s experience of space and time as well as the subject’s relations to both themselves and others. One’s experience of the everyday world which is given spatial and temporal coherence through our working acts, as described above, is fundamentally altered by illness. As Leder asserts: “Pain is the very concretization of the unpleasant, the aversive. It places upon the sufferer what I will term an affective call” (1990:73). The onset of illness thus presents a challenge as the shift in the lived body is complemented by an equal transformation in the quality of the world revealed by objects and goals which are said to “recede, mock me, proclaim my inability” (Leder 1990:23). No longer the tacit term in the point-horizon structure of experience, the body in illness becomes thematized as “Other” in and of itself; in other words it comes to occupy the “to” position of the from-to structure. The body in illness is thus asserted as an “alien presence” that threatens the routines and goals through which individual’s define their identity (Leder 1990:77). The accomplishment of the total, undivided self through one’s working acts in the outer world is disrupted as individuals in illness become unable to engage in meaningful activities and shared projects with others in their lives. The primary importance of employment as a culturally informed mode of being in the West (to be discussed in depth in chapter three) often entails that the notion of one’s working acts are equated with one’s profession. Further, the harmony between what one intentionally aims at and

what one accomplishes through which self-understanding is forged (Merleau-Ponty 2002[1962]:167) is fundamentally upset by the dys-appearing body. The implications for individual's experiencing illness is that a disjunction is initiated between the world as *opportunity* and the world as *actually given* as the habitual actions of the taken for granted body in health become more difficult. What has been described as a congealment of space and time occurs: the ecstatic body becomes forcibly rooted in the present attending to itself as other and the self loses its relations to goals and projects that were theretofore meaningful.

This process has also been referred to as a disruption in intentionality highly characteristic of illness experience. The nature of chronic illness means that the initial breakdown of everyday life through the surfacing of symptoms is sedimented into a structure of prolonged disruption in intentionality, i.e. in one's attitude towards the world. The disruption of illness is responded to by the self in form of a hermeneutic quest (Leder 1990) for meaning and reason. This search for a meaning to and understanding of the lived experience of illness is oriented toward the pragmatic goal of being free of suffering (Leder 1990:79).

It has to be emphasized however, that even in pain, which has been regarded as a purely individual experience, there is never a total collapse of one's life onto itself. The structure of experience as self-world relationship necessitates that there remains an intentional arc subtending our existence that commits us to an external and inter-subjective world (Merleau-Ponty 2002[1962]). Underscoring the experience of the dys-appearing body there is nonetheless an inevitability of belonging with the rest of humanity that informs a search for meaning and understanding of one's experience at the collective level. As Merleau-Ponty writes: "The body is at once a biological organism, a ground of personal identity and a social construct" (2002[1962]:99). The experience of pain as embodied beings is thus inseparable from one's life

as a whole as the opening quote of this chapter asserts. The focus for the remainder of the chapter will now turn to elaborating on the phenomenological understanding of the communication of lived experience.

Communication of Experience and the Importance of Metaphors

It has been said that communicating about pain enables one to make sense of a life that has come to be filled with suffering and thus begin to rebuild one's world (Good 1994). The difficulty however of communicating about what can claim to be an ultimately subjective experience is a dominant theme that runs through both the anthropological and clinical literature on pain alike. The employment of a phenomenological approach to exploring individuals' illness accounts is based on the stance that: "The spoken word is a genuine gesture, and it contains its meaning in the same way as the gesture contains it" (Merleau-Ponty 2002[1962]:213). The implication of this conceptualization for exploring the accounts of living with FM is twofold: on the one hand one is able to consider the narratives offered by the women interviewed as a genuine expression of experience; on the other hand, the gestural nature of language implies that their experience is actively constituted through their speech. The phenomenological perspective asserts that words and speech are not simply representations of thoughts but rather the actual accomplishment of thought in the phenomenal world (Merleau-Ponty 2002[1962]: 211). As discussed in the preceding sections, as humans we are intrinsically engaged in inter-subjective relationships, wherein our ability to understand one another through communication comes about through recognition of the reciprocity of perspectives. There is inherent in communication a taking up of another's thought through their speech that enables an empathic understanding of

one another (Merleau-Ponty 2002[1962]:208). Beneath the conceptual meanings of the words employed there is an inseparable existential meaning that discloses the very emotional essence of the individuals (Merleau-Ponty 2002[1962]). The implication of this concept for a study of illness is that one can consider words such as sufferer, victim or afflicted, employed by those who live in ill health, as revealing the altered existential stance of these individuals and not simply as meaningless categories or labels.

Along similar lines, in a manner reconcilable with the phenomenological perspective, Lakoff and Johnson's introspection into the underlying structure of communication postulates that as humans our conceptual system, both in terms of thoughts and actions, is fundamentally metaphorical (1980:3). Metaphors emerge as an essential means of understanding as they are grounded in physical experience and thus provide crucial links between everyday experiences and the over-arching conceptual system of a culture (1980:40). Dominant metaphors can therefore be thought of as not only providing a structure for verbalization but the very corporeal expressivity which correlates well with the phenomenological consideration of communication as yet another aspect of the complete mode of being-in-the-world. As Lakoff and Johnson pointed out metaphor serves to unite reason and imagination thus enabling individuals to partially comprehend that which is incomprehensible and needs to be understood by experiencing one thing in terms of another (1980:5). Furthermore, they argue that this system which allows one to understand a concept in terms of another fundamentally serves to hide aspects of that other concept (Lakoff and Johnson 1980:10). Alternatively, Merleau-Ponty highlights this obfuscation as follows: "Ambiguity is of the essence of human existence, and everything we live or think has always several meanings" (2002[1962]:196). The simultaneous process of highlighting certain aspects of experience while obscuring others has important

implications for understanding how culture shapes illness experience through metaphors. For example: the common cultural metaphor of “battling illness” calls to mind an active, aggressive response to ill health that fundamentally hides other aspects of the experience such as extreme fatigue and weariness.

The inseparability of conceptual and embodied activity is thus disclosed in the reliance on metaphors to mediate the different forms of illness (Jackson 1983:137). Through the use of metaphors there is a coalescence of the social, personal and biological aspects of being-in-the-world that provides an opportunity to reconstruct a coherence to one’s life world that has become disrupted by illness (Jackson 1983: 138). Further, metaphor is inherently a process of invention grounded in bodily experience wherein meaning emerges from the creative capacity of transcending readily given, social representations (Kirmayer 1992:335). There is a mutable character to metaphors that enable one to creatively transform one’s embodied experience. The meaning of the lived experience of illness is thus mutually shaped by the conventional metaphors of the broader social context in which one is situated and the idiosyncratic metaphors attributable to their own perspective (Kirmayer 1992: 339).

As the above paragraphs have elucidated, the phenomenological approach of exploring illness enables one to reconsider the experience of individuals within the broader context of their lives. Further, the assertion of communication as the constitution of one’s experience in the phenomenal world combined with the experiential basis of metaphors underpins the approach to considering the contents of the interviews as not merely representations but literally the active constitution of their experience. For the purpose of this research the starting point of exploration was delimited to individuals who had been diagnosed with the biomedical syndrome FM. The implementation of this category representing a set of common corporeal sensations meant the

adoption of an objectification of experience that while potentially problematic for a purely phenomenological analysis was necessary to artificially delimit the area of exploration. It is asserted that this delimitation does not however render the analysis any less relevant but rather discloses the commensurability of the personal and cultural due to the necessity of intersubjective recognition and construction of one's experience in illness, here represented by the diagnosis of FM. The assertion guiding this research is that Fibromyalgia represents an altered but nonetheless complete mode of being-in-the-world wherein the purpose of exploring these women's experience of living with this syndrome is to gain insight into the meaning of FM in their everyday lives. The following three chapters will sequentially explore in depth the concrete articulation of the over-arching phenomenological themes of experience of illness and pain,- the disruption in intentionality, spatio-temporal constriction and the hermeneutic search,- in the lives of the women who participated in this research.

Chapter 3-Falling Apart: The Onset of Fibromyalgia

The fidelity of our body's so basic that we never think of it, it is the certain grounds of our daily experience. Chronic illness is a fundamental betrayal of that trust (Kleinman 1989:45).

Elaborating on the notion of a betrayal of trust, illness has been variously posited as an ontological affront to the unity of oneself and a condition that impairs one's ability to live which initiates of a search on the part of the sufferer for legitimation within society at large (Hay 2010). As we are vividly reminded of our precarious corporeality the events surrounding the onset of illness seem to crystallize in our minds as the definitive moment of this betrayal. The common thread in the accounts of the onset of illness given by the women interviewed in this research was that it was represented as a moment of losing control of one's body, or of "falling apart". The manifestation of disruptive physical symptoms fundamentally challenges the integrity of oneself as previously discussed and initiates a split between the experience of self and body. Other common subthemes emerging in the accounts were communicating one's corporeal symptoms through vivid metaphors, ignoring the body in illness and continuing to maintain their respective employments despite their pain filled body as well as resisting adopting the label of "Fibromyalgic" or "disabled" individual. The focus of this chapter will progress through a discussion of these subthemes as expressive of the larger experience of losing control which is the lived, concrete articulation of the phenomenological notion of a disruption in intentionality for these particular women.

The Onset of Disruptive Symptoms

The onset of illness marks what Leder (1990) has termed the *dys*-appearance of the body

where the sufferer becomes acutely aware of their disrupted corporeality. The state of experiencing the world in health where our body fades to the background of our perception and we are engaged in the outer world is jarringly lost as we come to focus on our visceral sensations. The diffuse nature of symptoms associated with FM, ranging from pain, fatigue, sleep disturbances, digestive disorders, memory problems, depression and anxiety often results in what can be conceived of as a crisis of being-in-the-world that demands the construction of a narrative to confer order and sense to one's life (Good 1994:133). While the intensity and array of the symptoms of FM varied for each woman interviewed there was implicit agreement that there was a sudden marked departure from their normal state of well-being. The staging of their respective illness narratives revolved around the initial surfacing of physical symptoms that has been retrospectively traced back to a definitive moment in their lives, whether it is a particular calendar date or a life event. As Wendy describes the moment of dys-appearance:

It was three years ago [May 1st] and I literally woke up one morning and I thought I was getting the flu because my body was aching from head to toe. So I waited it out for about five days, and had the same feeling that the flu wasn't coming on. I didn't have a sore throat or a cough or fever so I went to the doctor and she said well lets wait another week. So at the end of the second week I still had this really bad pain from head to toe everywhere. I couldn't pin point where. So the second week, the end of the second week, I went for bloodwork at the end of the third week I went back to her. The end of the fourth week I went back to her. So now I'm a month and I'm really worried. The flu symptoms aren't coming out but everything's hurting all over...For me it was just like that. That's how fast it was. There were no warning signs that I can remember. (Interview November 2011)

What the above interview excerpt clearly highlights is the sense of unease that arises when one develops symptoms that persist beyond an expected timeline, the common experience of flu in this particular case. The expectation of warning signs speaks to the previously mentioned conception of illness as betrayal where the body, our most intimate ally, is thought of

as failing to provide clues to its impending dysfunction. Further, the notion of warning signs, commonly expressed through-out the interviews, discloses the intersection of the reductionist conception of health as being a state we individually maintain through hyper-vigilance over our bodies with the normative moral assumption that we seek medical care in advance of some precipitating crisis (Lock 1998:49). Additionally, the expectation of being able to predict ill health reveals the underlying cultural mandate for the maintenance of and enactment of control over the body (Crawford 1984 in Lock 1998:51). The moralization of illness is quite prominent in the debate surrounding Fibromyalgia which has been alternatively labeled “Fibbermyalgia”, “fibber” referring to the cultural caricature of a liar (Interview December 2011). Individuals with ambiguous conditions, such as FM, are often regarded as untrustworthy and their accounts of bodily pain are seen as fraudulent (Honkasalo 1998).

Interestingly, previous studies adopting a phenomenological exploration of Fibromyalgia in women have often remarked on the cultural, gendered expectation of women in the West to be open to the needs of others, of caring for others and of taking on responsibility for relationships (Lilleaas 1996 in Jingrot and Rosberg 2008:1520). This “female” manner of being-in-the-world has been accredited with the onset of ill health as women frequently give themselves secondary importance and ignore their own lived body. There is an inherent tension between the mutually contradictory expectations of women to be available or open in the social, intimate realm while being attuned to work as a primary culturally informed mode of being-in-the-world (Lilleaas 1996 in Jingrot and Rosberg 2008). The contradiction of cultural expectations for women to simultaneously regulate yet ignore their bodies presents a double standard that is evident through-out these women’s narrations of the onset of their respective illnesses. A consideration of the lived experience of FM enables a deeper level of analysis where the interview excerpt

presented above about the onset of that particular woman's illness is resituated in the broader narrative offered shortly thereafter:

My life changed dramatically. I used to, I was twenty-eight years at the time with a financial institution. So I worked at a bank as a senior lender; I was a mortgage expert. It was all I knew and I did that all my adult life and I loved my job. And then my father who lived with me for twenty years, single, so he was here when the children were born, when the children were growing up and when they left. My dad was always there. Then he got really ill. He got cirrhosis of the liver. He was an alcoholic. And I took care of him at home until he died. And then I drowned myself in my work to not feel any pain. So my life changed where I used to be a multi-tasker, go go go, really fast paced life to the complete opposite. And it's just put the brakes on everything. Everything's stopped. My life has stopped as I knew it (Interview November 2011)

A phenomenological exploration of the illness account above enables one to consider the entirety of the account where the contextualization for the onset of her particular illness emerges quite clearly as a turning away from life as it was before. The inherent difficulty in recognizing one's own patterns of being-in-the-world until the precipitation of an existential breakdown has been well documented (Jingrot and Rosberg 2008) and is clearly mirrored in the accounts offered by the women in this research. What makes Wendy's story unique is the way in which she poignantly expresses the cultural bias towards self-marginalization when she speaks of drowning herself in her work so as not to feel pain.

Also, there is a strong temporal element of hindsight to the onset of the illness, whether it is explicit or implicit, running through all of the interviews. As another woman, Claire, expresses:

It's like your body, part of it, is sometimes you just didn't listen to your body, to the clues and we just keep going and going and going until we hit the wall...So I kind of think mine was brewing and then it had that big push from the depression and that's my theory in my head (Interview December 2011)

The reference in the excerpt to not listening to one's body and continuing with their normal routines until a point of crisis despite the emergence of problematic symptoms once again reveals the contradictory assumptions of the body in Western culture. Implicit in the above quotes drawn from the interviews is the confluence of the reliance on visible or palpable pathology as the basis of illness in biomedicine with the cultural myth of control over bodily processes which serves to promote the notion that one can escape their corporeal dysfunction (Wendell 1996:93).

There was a notable diversity in the stories of illness onset given by the women participating in this research. The accounts ranged from engaging in too vigorous of physical activity or an injury at work to a viral onset. As Kleinman (1989:14) has noted illness idioms are forged from the dialectic between experience and meaning, in other words between corporeal processes and cultural categories. The idiom's most commonly presented for those whose onset of illness was precipitated by a physical injury reference the cultural idea of "pushing oneself too hard" or over-using one's body while the precipitating event was conceptualized as "the straw that broke the camels back" (Interview September 2011). As another woman, Martha, who recalls FM as emerging from a shoulder and neck injury sustained at work, summarizes: "It's like you have over-worked yourself so much and the pain is deep inside that you can't even push anything, everything is a struggle" (Interview November 2011). For others whose illness arose seemingly without motivation, as in the above excerpt, there was reference to a flu-like sensation where the concept of feeling "under the weather", an orientational metaphor referencing being down or unwell, became their point of reference for understanding their corporeal experience. The inherent inseparability of conceptual and embodied activity is thus highlighted through these women's reliance on the metaphors discussed above. Through conceiving of the onset of their

illness as “over-working” oneself or alternatively of being “under the weather” these women are drawing on conventional, cultural metaphors to creatively transform the initial emergence of debilitating symptoms into an intelligible experience.

The Communication of Corporeal Symptoms

Additionally, the communication of the experience of living with chronic pain and fatigue has been said to be a challenge that rivals dealing with the symptoms themselves as the language of everyday life does not adequately capture the experience (Jackson 2005:340). The difficulty of communicating about one’s lived experience of pain thus fosters a reliance on highly sensual and descriptive metaphors such as those drawn from the following interview with Karen. The changeable and diffuse nature of FM entails a vast repertoire of metaphorical representations, as can be illustrated by Karen’s vivid descriptions of the different intensity levels of her pain:

You know what it feels like when you’re in an airplane and its going up and down? The pressure on your ears. I’ll get that funny sort of feeling of being in an airplane. And then that’s kind of the mild one and I will get this feeling of fingers on the blackboard which makes you restless. It’s like you can’t relax because it’s like this, you just feel all...and then sometimes I’ll go: Oop! There’ll be an electrical shock in some part of the body that makes your, you know sometimes at night when your leg might go. Well it happens all over the place. And then, that’s all, those ones aren’t too debilitating. And then the worst one: it’s like you’ve been ironed with an iron. It’s a burning pain that just goes all over your entire body and you just...you just want to crawl in a hole and die. That’s kind of the magnitude and then it tends to go away a little bit. And then day after day it’s a little bit less, a little bit less (Interview December 2011).

As previously discussed, the absolute authority of diagnostic tests in the clinical setting has been critiqued as silencing the patients’ subjective voice (Leder 1990:147). This is especially

problematic in FM where sufferers need to take recourse to vivid metaphors to communicate their experience. Further, the invisibility of Fibromyalgia is implied in the metaphors chosen as there is a notable emphasis on the tactile and auditory senses, above expressed as pressure on the ears and fingers on the blackboard.

Further, until these women had received a diagnosis of FM, and thus a social label for their diverse symptoms, there was an absolute reliance on communicating their experience through metaphors, such as those discussed above. The length of time for a diagnosis of FM for the women interviewed varied radically from the expected clinical timeline of three months⁵ up to an extreme of eight years before a final diagnosis of FM was conferred. The duration of time it took for a diagnosis of FM interestingly correlated with the level of mutual trust and intimacy in the patient physician relationship. Those women interviewed who were diagnosed fairly early on had been with the same family physician for decades. They described their physicians as believing their symptoms were real because they had already built a foundation of trust and the physician was aware of their particular health related behaviour and help seeking patterns. As Claire explains her experience with the medical profession:

Yes, over twenty years [has been with her General Physician] and that helps too cause she knows that I'm not a slacker, she know that I'm not a whiner right so when I'm saying that I'm so tired she knows that its bad right...So you know, when I go in and say "I'm so tired I can't cope" she respected that. And that probably made a difference right. If I had to go to somebody new and they had seen me just as I started the process, "she's whiny", "she's always tired", "something always hurts" you know. Right. So I was lucky I already had that relationship and I think that's probably quite valuable in the whole experience because we get each other (Interview December 2011)

The power of belief on the part of the physicians could be credited with either initiating

⁵ As discussed in Chapter One, three months is the clinical timeline upon which, pending no other identifiable etiology for their pain and fatigue, their condition may be diagnosed as FM.

or forestalling the process of learning to live with a chronic illness on the part of their patients, a point which again speaks to the authority of social structures to either mediate or further erode one's life-world (Good 1994:118). Unsurprisingly, those whose initial and eventually prolonged encounters with the medical profession contained a sense of disbelief in their experience reported a noticeably higher degree of suffering in their narratives. A delay in the conferring of a diagnosis of FM, the social name for their pain-filled experience, here underscores the sense of liminality these women experience as they do not subjectively feel well yet they are not officially recognized as being either visibly or credibly ill (Honkasalo 1998:53).

The dys-appearance of the body in pain means that habitual actions appear more difficult to accomplish as the pain filled body comes to represent an obstacle standing in the path of normal functions and the achievement of projects (Leder 1990). The taken for granted-ness of health is confirmed over and over in these accounts where the women assert that they thought this patch of ill health would simply go away, reconfirming Kleinman's (1989) statement our inherent belief in the fidelity of our body. The predominant disruption in the ability to engage in meaningful activities and projects was manifested in their professional roles reconfirming work as a primary culturally informed mode of being-in-the-world.

Ignoring One's Body and Continuing to Work Despite Pain and Illness

The primacy of employment as a bench marker of one's identity in Western culture, a notion underscored by the assumption that economic independence is the epitome of adulthood, is a recurring theme through-out the interviews completed for this research. Work, in a meritocratic culture like Canada, often becomes equated with living a good, moral life wherein

non-work is associated with laziness and a bad life (Hay 2010:262). The women discussed the importance of maintaining employment within the context of ignoring one's own body in illness so as not to cause further disruption in their lives through the loss of their professional role which is an important part of one's personal identity. As one woman Wendy, a former mortgage specialist in her early fifties, describes:

So May one when I first started getting the symptoms, when I had the symptoms I continued to work and it was really really difficult. And I am very very hard on myself at work. I want perfection in my job. And I kept working and I would bring heating pads to work. And I had my own office and when a client would come in I would hide the heating pad.(Interview November 2011)

Wendy's story is echoed to varying degrees through-out the other interviews where these women speak of finding ways to accommodate their normal working schedule despite their growing discomfort and illness. In her particular circumstance, Wendy speaks of bringing heating pads to work to relieve the pain; other women reported either restricting the hours that they worked or limiting the duties they performed while on the job. What the quote speaks to is the over-arching cultural assumption that individuals approach illness with a stoicism and independence to continue to meet the societal demands of work (Hay 2010: 262). There is on the part of individual's suffering from chronic illnesses such as FM an enhanced sense of loss as they are unable to adhere to this cultural ascription. Their accounts can thus be said to confirm and perpetuate the linkage between productivity and moral worth that is so vital in the West (Hay 2010:262). The disruption caused by the onset of symptoms relating to FM is therefore initially relegated to their inter-personal relationships as they strive to maintain work which they define as an integral component of their lives. Therefore, through-out the process of seeking medical care and being diagnosed with FM there arises a shared sense of pushing oneself to continue in

the face of physical adversity. This commonality drastically highlights the obvious importance of work at both the personal and societal level in Western culture, as well as, the prevailing moral attitudes towards the body more generally.

The persistence of maintaining employment despite the emergence of the pain-filled body also subtly reconfirms the ambivalence toward work within Western culture as it has historically paradoxically been coined as pain's twin and it's polar opposite (Scarry 1985:169). As Scarry elaborates:

It [work] does, however, under all circumstances, and regardless of whether it is primarily physical or mental labour, entail the much more moderate (and now willed, directed, and controlled) embodied aversiveness of exertion, prolonged effort, and exhaustion. It hurts to work...Work is, then, a diminution of pain; the *aversive intensity* of pain becomes in work *controlled discomfort* (1985:171).

Continuing to work through-out the course of their illness has been understood alternatively as providing a haven from their pain-filled existence which confirms Scarry's notion of work transforming one's experience (Delvecchio Good 1994:53). Employment in this conceptualization confers the possibility of transcending their corporeal dysfunction through continuing to contribute to meaningful projects and thereby achieve a measure of self-realization within the broader community (Delvecchio Good 1994:53). Mary-Ann confirms this view of working when she states: "When I stopped working I started to feel emotionally, I started to feel worthless. Like no purpose in life because I'm not helping anybody"(Interview December 2011).

While the invisibility of chronic pain conditions like FM poses challenges for the legitimization of experience it simultaneously enables individuals to dissemble and conceal their pain-filled existence (Jackson 2005:341). There was a common cycle of working, needing time off and returning to work through-out these accounts spanning from months upwards to a decade

that indicates the often reported episodic nature of chronic pain. Further, performing to the cultural expectation of bearing one's pain and discomfort in silence paradoxically confers both a measure of respect and disbelief in the validity of one's experience (Jackson 2005:342). The subtle expectation of ignoring one's disrupted corporeality is described by Kathleen, a registered massage therapist in her late fifties, as follows:

The weekend I fell was Father's Day weekend and I was supposed to start back at [her old place of employment] on the Monday....long story short is that I did end up going back after a couple of weeks but I was not in any physical, mental or emotional shape to go back but I was afraid to disappoint my clients...but I still wasn't feeling right, my energy was low and physically I was hurting but I kept on going (Interview September 2011).

There is in the above quote an implicit recognition that returning to work is not the best course of action for personal health. However, the importance of being a good employee and performing well on the job trumps the necessity of taking time to recover, at least for the short term. The physical symptoms of pain and fatigue are often spoken of as not being enough of a motivating reason to leave their employment. Rather, the decision to leave work is precipitated by the manifestation of psychological symptoms associated with FM. These symptoms are most often related to memory troubles and are referred to as "Fibro Fog", which aptly describes these women's feeling of being unable to recall routine tasks at work or form sentences and words. As another woman Liane describes:

It took me a long time, really until this last year and a half when I haven't been able to work to do the things I should've done and what stopped me working wasn't the fibro it was my migraines...So, for me the fibro wasn't enough and it should have been enough. Because I really I wasn't functioning very well before the onset of this but it took not being able to read. To really have that full on stop sign going "you can't do the job" and to accept that I couldn't do the job. So, which was very hard but I mean I had been through ten years of on and off and these crashes and this needing a month or two off at a time and using my sick leave every year. (Interview

November 2011)

The notion of “falling apart”, expressing the over-arching experience of the onset of illness for the women in this research, stems partly from the occurrence of psychological symptoms which connects FM to cultural assumptions concerning mental illness as a form of loss of control, often seen as deviant. Additionally, the complexity of FM due to the somewhat staggering array of co-morbid syndromes associated with the syndrome is represented in Liane’s differentiation between her migraines and “the fibro”. The invisibility of FM in terms of physical markers often reifies the conception that it is a “false” syndrome, expressed in women’s reports of a mixed sense of acceptance on the part of co-workers and society more generally. Writing on the experience of individuals living with chronic debilitating illnesses, Manderson aptly summarizes the Western cultural expectation of the body as follows:

...to be considered healthy and productive-the two aligned in the social imagination- and accorded full social membership requires that people are in control of and can take care of their own physical bodies (2011:35).

Suffering on the part of these women with FM is compounded by the double experience of not being able to adhere to others standards in terms of a normal working day and not being able to accomplish what one sets out to do for oneself in the career or job. The sense of loss and disappointment is, for example, described as follows:

And suddenly all of your dreams, everything is just not there anymore. Then the pain of struggling every day, struggling with the pain, everything is different. (Interview December 2011)

The telic demand of the experience of pain which resultantly reorients one’s focus toward the body and away from the outer world is strikingly present in the previous quotation. The complexity of FM compounded by the unpredictability of symptoms is communicated in terms of these women gradually losing touch with both their bodies and the world of work. As Mary

succinctly asserts: “I was a lawyer that could no longer draft a legal document and I was not very happy about that” (Interview January 2012). What this quote reveals is the sundering of self and identity that occurs with the surfacing of symptoms that renders previously common tasks and abilities untenable.

Resistance to the Label of Fibromyalgic or Disabled

One of the questions I asked of the women in this research following their presentation of the beginning of their illness was what a diagnosis of Fibromyalgia meant for them at the time they were initially given the label. There was consensus that having a biomedical diagnosis was important in that it primarily gave credence to their experience through asserting that it was not an imaginary disorder. As Wendy said:

I think it was important to me because I didn’t know what was wrong with me. At least there was a name for what I had. It was important to know that yeah it is real. There is something wrong with me. It’s not just in my head (Interview November 2011).

The naming of the origin of pain, here represented by the label FM, has been said to enable one to seize the power to alleviate suffering and thus begin to reconstruct the unity of oneself and the integrity of their life world; a process clearly evident in the above quote (Good 1994:129). Another woman, Mary-Ann, expressed the importance of a diagnosis as follows: “I was relieved to know it was that, I was relieved to have an explanation for the fact that I was a hard driving person that couldn’t do it anymore.” (Interview December 2011).

What these two quotes drawn from Wendy and Mary-Ann reveal is the importance of achieving a validation for their experience as there is an underlying tenet in meritocratic societies

that associates incapacity with moral liability (Hay 2010:270). Conferring a diagnosis typically provides a reference point for both the individual with the illness as well as their intimate and larger social circle, for understanding the sequence of health-related events as they have unfolded and for conferring order to the disruption in their lives. In the accounts of these women, however, the initial relief at having a name for their experience and thereby having it acknowledged at least in certain respects is frequently closely followed by a rejection of that same label on another level. There is a juxtaposition of having FM versus “being a Fibromyalgic” that speaks to the problematic process of Othering individuals in illness that occurs on a societal level and thereby also on an inter-personal level. Kleinman summarizes this process as: “we place complex individual’s in simple, unidimensional roles as if this were all they are and can be” (Kleinman 1989:180).

The ambiguity surrounding invisible chronic illnesses, of which FM is a prime example, often leads individuals’ to reflect on whether to disclose their status as individuals with FM to other people. As one woman, Karen, a retired mortgage specialist in her late fifties, stated:

The one thing I could never decide... is it better to give it a label or not? Like somebody said, the fellow on the radio said that doctors jokingly refer to it as Fibbermyalgia. That do you want to say that you have it or do you want to say oh I suffer from ill health?...And I could never decide in my own mind which was better because as long as it gets negative, some people say I have Fibromyalgia and everyone goes, “Oh yeah right.” Maybe it’s just better to say I have really bad migraines or whatever. Maybe that is more accepting (Interview December 2011).

Karen here hints at the underlying assumption surrounding physical inability in Western culture where through the processes of social exclusion, stigma and discrimination there is an inference of social inability (Manderson 2011:36). The loss of physical well-being, underscored by an incapability to maintain employment and thus autonomy on the broadest cultural level,

comes to be seen as signifying a decay of the self that calls into question these women's social roles. Additionally, the dys-appearance of the body in chronic illness, and FM particularly, comes to be regarded as disclosing not simply the manifestation of disrupted biological processes but more ominously the symbol of a morally flawed character (Manderson 2011:35). The disruption in intentionality through losing the capability of working either partially or completely is translated into a loss of the sense of self related to working. The desire to be recognized as members of their respective employment, with all of the cultural identity markers, is discursively disrupted; at the same time, this disruption means that the afflicted women are confronted with the problem of how to identify themselves. The disjunction between self and body brought on by chronic pain along with their fatigue ultimately culminates in a crisis of self that Mary describes as follows:

So very much of my sense of self was of somebody who was very capable academically...I think it would be hard for anybody but for somebody who always had been praised and appreciated for being bright I was not so bright anymore and I really felt, I think that was harder than just about anything else was realizing "wow I really can't think clearly anymore, I can't speak clearly." My brain doesn't work. That was really hard. (Interview January 2012)

There is a certain resistance to adopting the label and thereby performatively assuming the role of Fibromyalgic or even disabled individual that quite explicitly runs through the narratives. Confronted with the choice of adopting the category of being an individual with FM there emerges consistently a profound revaluation of labels on all levels, poignantly expressed here by Liane:

Way too much is wrapped up and it's the same as the health label. And once you realize all those things are the same, labels don't matter. Labels are meaningless. You have to deal with the person you've got in front of you as a person. Not as what they do or their illness or who they live with of you know what their past choices have been. It's huge. Certainly North American society is far

too wrapped up in career and having to be strong and maintaining the nine to five work schedule and the no flexibility in that. We're creating our own entire problem. (Interview October 2011)

The sense of aversion to admitting to living with FM and to adopting the category of disabled individual is itself phenomenologically rooted in a dialectic of self and other. Our innate corporeality entails the possibility of being reduced to a disrupted body, in other words, becoming objectified in the gaze of others (Merleau-Ponty 2002[1962]:193). The French writer Emile Zola has critiqued the assumptions underlying the identification of individuals as disabled in the following words: "Others react to him with great ambivalence, ranging from gross inattention to embarrassing over-concern" (Zola [1982] in Kleinman 1989:168). Mary, in her account of living with FM, echoes this sentiment as follows:

You don't have to keep asking me[if I'm Ok] because it's singling me out and it's, I know it's meant well, but can you see how that's, you're not asking somebody else oh are you ok? And it's making me feel disabled.. (Interview January 2012).

The inherent inter-subjective nature of existence entails the possibility of transference of the dys-appearance of the body from a strictly corporeal realm into the realm of the social, as Mary clearly expresses. Thus, while the disruption in intentionality was manifold for these women in terms of their chosen professions it certainly pervaded all aspects of their lives. The rhythm of the lived experience of social life, typically characterized by the movement from work to leisure and activity to rest, becomes upset by the onset of serious illness such as FM (Good 1994:131). The following chapters will therefore be devoted to describing the ways in which their intentionality in the world was reoriented towards the pragmatic goal of being free of pain. The discussion will approach this topic through elaborating on the articulation of the phenomenological themes of spatio-temporal constriction and hermeneutic search.

Chapter Four: Pacing Oneself: the Everyday Experience of FM

As I go through the day, my extended body ebbs and flows, now absorbing things, now casting them back onto shore. I do not notice my body, but neither do I, for the most part, notice the bed on which I sleep, the clothes I wear, the chair on which I sit down to breakfast, the car I drive to work. I live in bodies beyond bodies, clothes, furniture, room, house, city, recapitulating in ever expanding circles aspects of my corporeality. As such, it is not simply my surface organs that disappear but entire regions of the world with which I dwell in intimacy (Leder 1990:35).

The above excerpt drawn from “*The Absent Body*” vividly describes the depth of disappearance characteristic of the ecstatic mode of being where one is centrifugally oriented towards the world. As discussed in chapter two, phenomenology holds that we intrinsically inhabit space and time as the body is our means of being-in-the-world thus there are spatial and temporal dimensions to all modes of experience. The implication of this concept is that the emergence of the dys-appearing body alters the articulation of the synthesis of space and time, which is performed anew in every instant through our actions in the outer world. Illness therefore presents a marked departure from the ecstatic manner of engaging in the world wherein the loss of association with external goals and activities such as work, as mentioned, is correlated with a spatio-temporal constriction in the experience of individuals living with FM. The ever expanding circles of corporeality referenced above experientially shrink in circumference as one is called to attend to one’s body. Further the intimate regions in which one experiences everyday life take on a shade of inaccessibility confirming Scarry’s portrayal of pain as “unmaking one’s world” (1985). In addition, there is a marked progression from the onset of “falling apart”, the focus of chapter three, to adapting to life with FM as a different mode of existence complete with its own, altered articulation of space and time that builds on the disruption in intentionality characteristic of chronic pain. The over-arching phenomenological theme of spatio-temporal constriction concretized in these accounts as learning to live with FM through pacing oneself is therefore the

focus of discussion for this chapter. This articulation manifested predominantly in their personal, social lives is discussed here under the following themes; the initial spatio-temporal constriction of FM, the correlating difficulty in communicating about FM, the eventual dis-engaging from social activities and relations that enables one listen to one's body and finally a re-valuation of priorities and relationships.

Spatio-Temporal Constriction

The experience of space and time is thought to be fundamentally transformed by the onset of chronic illness. This transformation occurs fundamentally in the particular spaces accessible to and used by the acting self in the present. As discussed, the synthesis of time and space is consistently being accomplished through one's working acts in the outer world (Schutz 1971) which has considerable implications for individuals with FM. The most notable and life altering shift repeatedly reported in studies exploring women's experience of living with FM is that of the shift from an *active* to a *passive* lifestyle (Asbring and Narvanen 2003). The overwhelming of personal space and time by the presence of the dys-appearing body renders the possibility of engaging in social activities untenable as the daily tasks of living become the focus of everyday life. Eliza speaks of this constriction in her life:

Well I can't do too much because if I go out that's my whole focus of the day if I go anyplace. So like I'll, most of my time is taken up with the meal, getting the meals ready, trying to get dressed and look after myself. So there's not too much socializing. (Interview December 2011).

In addition, to be forced to ask for help with the fundamental daily needs of life has been previously linked with a perceived lack of understanding on the part of others that challenges one's sense of dignity (Ohman, Soderberg and Lundman 2003:538). In other words, the necessity

of depending on others who may not recognize the severity of symptoms associated with FM and the practical limitations it places on one's life adds to the experience of a constricted world.

Mary speaks of her experience as follows:

So here's a big cultural observation for you Ok. You get cancer, you get casseroles, you get people offering to drive you to appointments, and you get all kinds of great stuff if you get cancer. And I know this because of having seen what happened with my friend J. You have chronic fatigue and you can't even comb your own hair and you can't read, and there's not really a sort of cultural reference for what you do as a community to help somebody in that situation. It's just not in people's consciousness that you can't do stuff. (Interview January 2012).

What is overarchingly referred to in the above two quotes from Eliza and Mary is the need to abandon their normal pace of life due to a disrupted corporeality. The dys-appearance of the body in FM recurrently brought to the fore by the episodic nature of the associated symptoms-which vary not only day to day but hour to hour-thus exacerbate the spatial and temporal constriction of these women's lives. Implicit in the cultural expectation that one maintain control over the body's intimate processes is the additional expectation that one perform to the increasingly fast pace of life in Western culture, an expectation which assumes a healthy, able bodied individual (Wendell 1996:38). While there is an explicit cultural understanding of the experience of cancer as an acceptable deviance from this standard, a theme evident in all of the interviews, there is a notable lack of transference of understanding to individuals with FM. In sum, we can say that the recurrent contestation surrounding FM appears to be grounded in the biomedical "invisibility" of the syndrome. This is concretely expressed by the interviewed women in terms of a lack of cultural referents for both those living with FM and society at large.

When I asked the women who participated in this research about the experience of a typical day in their life the overwhelming response was that a typical day is *atypical*. In the lived

experience of space and time, the distances and rhythms of daily life are experienced in reference to the state of one's body which presents a challenge to individuals as they adjust to an altered body (Raheim and Holland 2006:753). The variation in the levels of fatigue and pain, amongst other symptoms associated with FM, tends to create a disjunction in the experience of one's potentials. The experience of the dys-appearing body in FM, referenced by one woman as a "roller coaster" (Interview December 2011), breaks the normal association of inferring present capabilities from past experiences. As Claire states:

My productive day is so short compared to what I used to have and that kind of bothers me. Yes, drastic changes into what can get done in a day. And evenings I tend not to do anything and that bugs me. What I do in a day now I used to do like on my way home after work you know.
(Interview November 2011)

There is a consistent temporal element to referencing what one was capable of doing that is markedly centered around the nine to five working day typical of North American culture. In addition, the consistent reference to the productive day and a sensation of being bothered reveals the tension between the measured, clock and calendar time of society at large and lived, subjective time (Hellstrom and Carlsson 1996:422). The inherent assumption that we all inhabit a familiar world is challenged by the onset of illness leading to a potential distancing from friends and family, as personal time and space lose their orientation to others. The changeable nature of FM contributes to this distancing as Wendy reveals:

So my whole social life has changed. I don't go out with friends a lot anymore. I stay close to home. Sometimes I'm afraid of it, the fibro, like what if I really flare up when I'm out? So it really has made me stay close into my own home. So I am not as social. (Interview November 2011)

The above quote clearly expresses both the disruption in intentionality of engaging in meaningful activities with one's social circle as well as the spatio-temporal constriction characteristic of the

recessive mode of being-in-the-world. The disjunction between the concepts of self and the body is evident in the objectification of the embodied experience of FM as “the fibro”, representing the illness as an entity that has seemingly taken on its own agency. The emphasis on remaining close to home reveals the difficulty in making choices, which arises from the variability of symptoms of FM. The unpredictability of the appearance of pain leads to a situation in which management strategies that worked in the past, even mere hours or days ago, are often ineffective in the present (Cunningham and Jillings 2006:264). For the afflicted women there is thus a congealment of lived experience in the here and now due to their disrupted corporeality that disturbs their intentional time and renders future plans uncertain (Hellstrom and Carlsson 1996:421).

Spatiotemporal Constriction and the Difficulty in Communicating about FM

The initial withdrawal from social activities, brought on by the inability to definitively commit to plans eventually translates into a restriction in one’s overall social circle. Mary expresses this as follows: “You know people are busy and eventually if you say no to enough invitations and don’t reach out yourself things do change in a relationship.” (Interview January 2012). The inherent difficulty in communicating about pain and fatigue levels, spoken of at length, therefore colludes with the acknowledgement of responsibility for mutual engagement in relationships to exacerbate a sense of frustration at not being able to maintain life as it was before FM. Martha speaks of this social distancing as follows:

You are more focused on the pain because you have pain but you can’t go somewhere and stay for a long time and even when invited somewhere you just cut yourself and say I won’t be able to. So by you cutting yourself you are putting a distance on people as well so that if there is

something they're not even going to tell you I mean because you have refused several times because you are pushing yourself because they're not understanding you. So that's how it is. (Interview November 2011)

The shift in characteristics of space brought on by the restriction of mobility in chronic illness is well established in academic literature emphasizing that an individual's sense of space becomes distorted as their physical space shrinks (Toombs 1992 in Honkasalo 1998:37). Additionally, our biologically grounded upright posture informs a certain manner of being-in-the-world, such that a permanent shift in posture to a lying or sitting position necessarily entails a shift in social hierarchy. A disruption in one's ability to maintain an upright posture diminishes the experienced space which becomes synonymous with an inability to manage oneself in Western culture (Honkasalo 1998:37). The invisibility and incommunicability of FM correlates with the incapacity to undertake the routine, taken for granted tasks of living and thus intensifies the sensation of aloneness and moral disruption:

Absolutely, I look one hundred percent. You would never know there was anything wrong, you'd never know that I have trouble getting out of bed in the morning that I have to plan my day like this, that by two o'clock I lose the use of my arms. That I can't pick stuff up after a certain time. It's very difficult to communicate and to even describe your pain and fatigue levels to somebody else. (Interview November 2011)

The spatio-temporal constriction common of FM is quite evident in the above passage drawn from an interview with Liane: She speaks of having difficulty maintaining an upright posture, revealed as being unable to get out of bed, and how this combines with the collapsing of the possibility of engaging in activities in the outer world, here spoken of as losing the ability to use her arms.

This shrinking of lived space is however, never complete as Scarry explains. The faculty to communicate, to speak inevitably connects the self with a world:

So long as one is speaking, the self extends beyond the boundaries of the body, occupies a space much larger than the body (Scarry 1985:49). It is the human voice which carries experience from isolation to intersubjective space (Honkasalo 1998:47).

In the case of sufferers from FM and other chronic illnesses, the social constriction in terms of physically meeting with friends and family is broadly countered through a shift to reliance on contact via the phone or e-mail. Difficulty can become insurmountable in FM however, when the fatigue is overwhelming and the spatial constriction threatens to mute the self altogether: “What makes it even more difficult is that when you’re very very tired you have trouble articulating it, you just have a lot of trouble expressing anything” (Interview with Mary January 2012). The partial or total restriction in ability to communicate due to fatigue and “Fibro Fog” is echoed throughout the interviews as one of the most frightening aspects of FM, as it foreshadows a potentially complete collapse of the ability to engage with others. The difficulty in communicating their experience extends the dys-appearance of the body in FM into all aspects of their lives, as reflected in Kathleen’s comment:

There’s an overwhelming sense of despair and anxiety and grief and sadness and the other thing is you feel so alone because no one, not even the doctors, really understand the degree of symptoms. (Interview September 2011)

There is throughout the interviews an over-arching notion of becoming distanced from oneself and others as the un-intelligibility of chronic pain becomes a totality of experience. The above reference to feeling alone confirms previous research asserting that: “Solitude is one of the most usual companions of pain” (Honkasalo 1998:45). Further, suffering induced by pain is conceived of as limiting subjects’ perspectives as they are called to reflect on their body and become increasingly isolated from all that is without connection to the experience of suffering (Buytendijk 1962:25).

Disengaging from Social Activities to Listen to One's Body

The experience of the chronically ill has been said to be primarily informed by how they experience both their home and work as these are typically the dominant spaces of their life world (Moss and Dyck 2002 in Crooks, Chouinard and Wilton 2007:579). An important emergent subtheme under the experience of learning to live with FM through pacing oneself was that of learning to listen to one's body. Thus the disruption in intentionality characteristic of the emergence of the dys-appearing body ultimately permeated not only their professional lives but their personal lives as follows:

You push yourself in the beginning I mean because you don't know that it's going to last like that. I was on light duty at work, still able to do the light duties, and I would still come home and try to push myself to do some clean up and something in the kitchen. I want my children to come home and find that the food is ready as usual as a mother you want everything to be at home and you want to organize yourself and everything. But then the more you do the more you crash yourself, the more you're down for days and you find yourself you can't do it anymore. The more you change, you become angry to people...then you find you are losing your family as well
(Interview December 2011)

The cultural importance of work, the focus of the preceding chapter, is referenced here again as a project of primary import while the activities and roles in one's personal life are often secondarily referred to as extraneous and a source of tension. The initial prioritization of working life over personal activities seen in the interviews with women in this research parallels that of other studies on FM where working was seen as an integral marker of health and self-esteem as it provides human contact and a sense of contributing to society (Mannerkorpi et al. 1999). Many women describe the disruption in intentionality and constriction in their ability to commit to future plans in terms of a sacrifice of their social self:

The first thing to go was planning any social activities with friends cause I never knew how I was

going to be feeling so I just didn't plan anything and didn't go out often so my social life suffered first. It was the first casualty before my work life. (Interview with Liane, November 2011)

Further, the above reference to pushing oneself in the beginning underscores once again the belief in the fidelity of one's body where despite the emergence of pain and fatigue there is a refusal to acknowledge the severity of one's corporeal dysfunction. The findings of previous studies exploring FM have asserted that a diagnosis enables one to move forward with their lives through learning to live within the boundaries imposed by the condition (Cunningham and Jillings 2006:263) Thus, the temporally prolonged nature of FM, as a chronic illness, was found to eventually call for a revaluation of existing affective attitudes towards one's body, exemplified in the following quote from Mary:

My general attitude before in life has been that hard work will get you out of just about any jam you will find yourself in but when you have a fatigue problem that actually gets pretty self-defeating (Interview January 2012)

What this excerpt clearly reveals is the sundering of the world as opportunity brought on by the fatigue and pain of FM. The taken for granted ecstatic mode of being-in-the-world characterized by the disappearance of habitual actions is re-assessed as one becomes seized by the vital functions of the body. There is an acknowledgement that the stoic, independent approach to both work and life in general, referenced above as hard work, is not a viable or desired solution and comes to be regarded as self-defeating. The process of learning to live with a chronic illness, such as FM, thus transcends simply managing symptoms and requires an active adjustment to a new mode of being-in-the-world (Svenaeus 2000:135). This altered mode of existence requires constant vigilance over the body which Liane expresses as follows:

It takes so much planning to go anywhere that that in itself is exhausting and for someone who

doesn't have much energy it's really overwhelming. Cause that's where your energy goes is to planning your day, trying not to cause flare ups and trying not to make an already bad situation worse (Interview November 2011)

Life with FM is paradoxically conceived of as both increasingly unpredictable due to the episodic symptoms that render definitive plans uncertain, and as more regular, due to the required planning efforts (Soderberg, Lundman and Norberg 1999: 580). In essence there is a fundamental loss of spontaneity in FM in terms of goals and social activities as one is called to attend to one's body.

A predominant characteristic of chronic pain conditions is the temporal intensification of pain as well as changes in the manifestation of symptoms within the body which recurrently "puncture the scene with novelty" (Leder 1990:22). The complete or partial withdrawal from both work and social relations, while experienced as a loss was alternatively credited as providing these women with the time to listen to their bodies and thereby gain a greater understanding of their illness experience. As one woman, Claire, states:

Once I was off [work] you're far more in tune with your body when you have the time to listen because when you're working you're stressed and that we don't put things together and we don't acknowledge our bodies' right? (Interview December 2011)

Mary-Ann further confirms the necessity of acknowledging ones corporeality in the etiology she provides for her experience of FM:

Yeah, listen to my body. I used to ignore my body and say, my body would say "well you've got four social occasions at night in a row and you worked full time and you've got the kids and you should stop." And my mind would say "no I'm going on." And my body would be saying "stop." And I really think the fibro was my body's way of saying "I'm sorry but we're not playing with you anymore." (Interview November 2011)

There is a notable emphasis on auditory metaphors, such as listening to one's body and being in

tune with one's body in the above excerpts, which runs through-out the interviews. The reliance on one's auditory sense presents a departure from the primacy given to the visual sense in Western culture which perhaps underscores the recurrent issues surrounding the lack of visibility of FM. In addition, the body in FM implicitly referred to above as being unruly is conceived of as exerting a will of its own that calls for a complete revaluation of approaches to activities and goals:

It's, you just have to break it down into a series of manageable steps and do one. And Ok I need a rest Ok, have a rest. Ok I'm feeling alright again off I go. It's very hard to learn how to do that effectively but it's a skill like anything else; you learn it, you practice it, it becomes second nature. You just sort of do it. (Interview with Mary, January 2012)

The reference to the acquisition of "pacing" as a skill highlights the interplay of spontaneity and sedimentation that informs existence. The incorporation of novel habits and skills, here the ability to break activities into manageable steps, reconfirms the affective call of the world to modify one's corporeality. The skill of pacing characteristic of the process of learning to live with FM thus becomes incorporated into the potential uses of the body until it finally becomes "second nature". In addition, the recurrent necessity of surveying one's corporeal processes for these women coincides with Kleinman's observation that: "Chronic illness is an ongoing process in which personal problems constantly emerge to challenge technical control, social order and individual mastery" (1989:144).

The metaphor of "pacing oneself" calls to mind a spatial and temporal rhythm of measured steps that confers a degree of order and control in the disrupted lives of FM sufferers. The development of the ability to pace oneself thus creatively transforms the sense of loss and despair into a measure of empowerment:

Not trying to do everything at once, just a little bit at a time. Its good now because I can sort of turn the dial down when I need to. So if I start feeling that achy pain, well then it's just telling me something, "you need to stop now. You have to go lie down. You cannot finish the vacuuming, you cannot finish your meal, your cooking." (Interview with Wendy, November 2011)

Further, the telic demand of pain, which necessitates a consistent revision of ones plans for activities, has been described as exacerbating the disruption in lived time, sometimes leading to a dissolution of the temporal structure of experience. Claire clearly asserts this in the following statement:

Major planning all the time. All the time. Which makes it hard because sometimes you feel like you're not living in the moment right? (Interview December 2011)

What the quote implicitly refers to is the disjuncture which appears in the experienced self with the emergence of the dys-appearing body: "No longer absent from experience, the body may yet surface as an absence, a being-away within experience." (Leder 1990:91). In the experience of pain, the body appears in experience, but it does so in the form of a denial of its normal functioning, acquiring an alien presence. As it remains simultaneously the locus of the experiential present, a surreal sensation of "not being where one is" ensues.

The insistence on dividing tasks into a series of steps, commonly spoken of as "pacing oneself" becomes a necessity due to the profound fatigue associated with Fibromyalgia. One of the main underlying symptoms of FM is the sleep disturbance which translates into an inability to get the restorative sleep necessary for recovery from mentally and physically tolling activities (Crooks, Chouinard and Wilton 2007:583). Further, the level of pain and cognitive functioning were commonly said to correlate with levels of sleep: A good night's sleep can either make or break the plans of the next day for these women, reaffirming the uncertainty associated with FM and the necessity of continually listening to one's symptoms. Eliza confirms this sensation of

being at the mercy of the disrupted body in her statement:

I usually if I want to go someplace I will say maybe I will go and I wait to see that morning if I can go. (Interview November 2011)

Learning to live with chronic illnesses has been posited as a process of adjusting, through a persistent reconstitution of one's bodily knowledge that is directed toward "keeping open a future of possibilities" (Ironsides et al. 2003:180). This process is strikingly evident in Mary's statement that: "Fatigue prioritizes things. You know you're very foolish if you have very little energy and you waste all kinds of time and energy doing things that are not important to you." (Interview January 2012).

What ensues during the process of learning to live with FM is an over-arching revaluation of one's lived experience along the lines of priorities and values that speaks to the absolute aversiveness of the experience. This is echoed in an analogy between pain and death, drawn by the Dutch phenomenologist Buytendijk: "The phenomenon of pain as an experience forces man to reflect in the same manner as death forces him to do so" (1962:20).

Revaluation of Life Priorities

I really just appreciate what I have so much more. I think I'm a lot more focused on what I do have than what I don't have because when your life shrinks to the degree that you do, really to do anything that you enjoy, talking to a friend on the phone, watching TV, watching a movie, reading a book, reading a really, crappy trashy book. When you need to budget energy to that, to that point, where you need to go lie down for an hour first in order to be able to do that thing. Oh my gosh, I just feel like I have a really full and rich life now. (Interview January 2012)

The above passage, drawn from an interview with Mary vividly expresses the spatial and temporal elements of the experience of living with FM. The recessive mode of the body in illness inevitably going along with a transformation in the quality of the experienced world is captured in her reference to the shrinking of her life-world. The constraint on the capacity for engaging in activities in the outer world is here expressed temporally as needing to budget one's time and spatially through reference to activities that are restricted in terms of motility, such as reading a book and watching a movie. The process of learning to live with FM is metaphorically referenced above as needing to budget energy in order to enjoy a rich life which implicitly reconfirms the importance of economy and productivity albeit in an altered manifestation. Living with a chronic illness has often been reported as a moralizing lesson which teaches individuals about living a life filled with those things that matter most (Ironsides et al. 2003:179). Karen speaks to this notion:

I think the biggest thing is it's Ok to do nothing. You don't always have to be doing something....I was always engaged in something that I thought was important that probably wasn't. And it's very easy to get caught up in many things and not you know, the personal relationships, the family, the things you can do for the community that those things have real value rather than running around at work writing the fifteenth report or the fifteenth draft or something that you kill yourself to do but really wasn't that meaningful when it was done.
(Interview November 2011)

This excerpt from an interview with Karen reconfirms previous research wherein successful coping strategies for individuals with chronic illness is often manifested through identification of and maintaining participation in vital parts of their lives (Raheim and Holland 2006:756). The re-prioritization of activities and goals often translates in the accounts of the women interviewed into a sense of liberation from cultural expectations and requirements imposed by others which speaks once more to the creative transformation of loss into gain. Mary-Ann summarizes this

process:

But I found that it really has made me more relaxed, it has made me less materialistic, more grateful for what I get. Yeah, I, like they always say about illnesses, and I have a nephew that just went through cancer and he says the same, it really makes you a better person all around. You are more empathetic toward people. Because when you're in chronic pain it's hard to dump on somebody because you think hey they could be too. So no I found it in a funny way a boon. (Interview December 2011).

As the initial surfacing of symptoms associated with FM sediments into the prolonged, dys-appearing body the distancing from the hectic pace of everyday life encourages an altered appreciation for what remains in their lives. The revaluation of time and space initiated by the onset of FM, which immediately calls for a shift in activities, eventually translates into a questioning of the self within the context of social relationships. The sense of self at this level of analysis is the social, relational self that is constituted inter-subjectively. The onset of FM fundamentally calls this into question for sufferers as they become increasingly distanced from others. As Kathleen states:

It's just...you lose yourself. You become a shadow of yourself and that's what people would say to me. But it's not easy to see your loved one go from being really strong and vibrant and being able to work and having success and then the next thing you know their whole world is torn apart. (Interview September 2011).

The challenge that FM presents to one's sense of self is best understood in the context of our inherent intersubjectivity where our possible selves emerge in a relational process that simultaneously confers potentialities of creation and destruction (Rahim and Holland 2006:754). This process is evident in the above quote drawn from Kathleen where the dys-appearance of the body in FM has permeated all aspects of her life, here confirmed by friends and acquaintances noting that she was a shadow of her former self. In connection with this, many sufferers from

chronic pain carry a sense of anxiety of being perceived as different from their previous selves in health that compounds the distancing and isolation common of chronic illnesses (Ohman, Soderberg and Lundman 2003:534). Claire poignantly expresses this crisis of self in reference to past capabilities in the following excerpt:

I still have those old standards sometimes and I think “well, why am I tired?” I shouldn’t be right, but it’s the old, you’re not in Kansas anymore. It’s a whole new place. That old normal is not on the menu, you can’t get that anymore. Right? So that’s part of you have to adjust to what is reasonable now and what you’re dealing with and as much as you want to it serves no purpose to compare yourself to your old life. Of course you do it, but what does it get you? You just have to say “In my new normal I can do this, I can’t do that and that’s it.” That’s what’s on the menu and not that other stuff. (Interview December 2011)

The risk of being reduced to a disrupted body in the gaze of those others which form one’s intimate circle colludes with the self-imposed limitations due to maintaining vigilance over the body thus concretizing the disjunction between self and the everyday world as these women learn to adjust to a life with FM. Throughout the interviews with the women who participated in this research there is an explicit recognition that the onset of symptoms associated with FM and the prolonged nature of the syndrome has revealed the fault lines in social relationships. Liane summarizes this as follows: “You find out quickly who your friends are. Who understands and who doesn’t.” (Interview October 2011). The persistent ambiguity surrounding FM grounded in the invisibility of the illness challenges common perceptions of the ill person. In the experience of the women living with FM in this research the ambiguous perception of their condition initiates a purging of unsupportive relationships in their lives. The extreme levels of fatigue and pain, spoken of before in terms of a need of prioritizing activities and goals is here concretized in their social lives, as Mary-Ann states: “I guess too that you make a conscious effort to support yourself with supportive, non-competitive people” (Interview November 2011).

The disjunction in lived experience of space and time thus ultimately entails a process of re-adjustment and the creation of altered, common ground in interpersonal relationships (Raheim and Holland 2006:752). Karen confirms this revaluation of relationships as follows:

I would say it's being much more aware of yourself and how things affect you. And even some people are negative people and some people are positive people, and it's better to be with those that are positive. You don't have energy to waste on those that are just negative all the time because you only have so much yourself [energy]. (Interview November 2011).

The preceding discussion has endeavoured to show that there is at play in the experience of learning to live with FM a simultaneous constriction and expansion of both space and time, underscored by the shift to the recessive body. The revaluation of priorities in life that is a dominant theme in the interviews with the women who participated in this research translates into a certain altered sense of appreciation of lived experience both spatially and temporally. The initial necessity of disengaging from previously important activities and social relations has given these women the time to attend to their bodies and thereby gain a measure of understanding of their diverse and episodic symptoms. Further, the dys-appearing body here coincides with this spatial and temporal distancing from the normal pace of everyday life enabling the women to reflect on the over-arching themes of Western culture. This removed vantage point translates into a purging of both unsupportive relationships and self-imposed attitudes in their lives which eventually highlights those relations and goals that are most meaningful to them. Although the ever widening circles of corporeality spoken of at the beginning of this chapter remain constricted in a sense the interior of these circles is gradually imbued with new meaning and purpose. The process of creating this sense of understanding of their complete life world is academically spoken of as the hermeneutic search, which forms the focus of the next chapter.

Chapter 5- A Journey: Understanding the Experience of Fibromyalgia

Healing is not per definition an absence of disease, but healing covers the process of engaging with symptoms, health professionals, relatives and friends, work places, and future life visions etc in order to manage a life in distress and to create meaningful relations for one's self. (Rosir 2010: 138)

The above quote clearly summarizes the complexity of the process of regaining a measure of well-being in one's life after the onset of illness; a process that involves physical, social, and existential dimensions. The initial stages of the onset of FM and being in illness for these women, the focus of the preceding chapters, thus eventually is transformed into an experience of overcoming their illness in a certain sense. This process of actively engaging in restoring their sense of well-being parallels that of other studies where the absolute focus on illness experience characteristic of the initial stages of chronic illness is gradually superseded by a renewed participation in life as individuals learn to cope with FM (Raheim and Holland 2006:756). Therefore, the third over-arching theme emergent from the research was that of conceiving of one's lived experience of FM as "a journey" or "a long road" toward restored well-being. This broad theme is comprised of subthemes focusing on the diagnosis initiating the search for health, regaining one's sense of control through self-education, the reliance on both allopathic and alternative medicine to alleviate the symptoms of FM and the role of sharing knowledge of FM with others via a support group. The remainder of this chapter will thus turn to a discussion of each of these subthemes as elucidating the lived experience for these women of the phenomenological motif of the hermeneutic search.

The Importance of Diagnosis as Initiating the Search for Meaning

The conferring of a diagnosis of FM has been previously discussed within the context of enabling sufferers to transcend the limbo of unease with their body through initially legitimating their subjective experience. Additionally, the diagnosis can be seen as an important turning point in the reconstruction of one's life world that initiates movement toward the goal of being free from pain. The process of creating order from the chaos of a life disrupted by debilitating illness is conceived of as a movement from diagnosis, where the responsibility for meaning is initially placed on the healthcare professional, to a gradual integration of new personal meaning and responsibility on the part of the suffering individual (Bullington et al. 2003:327). For individuals with contested or misunderstood conditions, of which FM is a prime example, the illness experience and associated health seeking behaviours are best understood as a continual social healing process (Risor 2010:137). The following quote drawn from Martha reveals the decision to shoulder individual responsibility for one's illness:

You find yourself helpless, hopeless, you can't move forward you can't do that. Then eventually you say. "Ok I have to accept that this is how I am going to live so how can I help myself?" (Interview November 2011).

The clinical ambiguity surrounding FM along with the diversity of symptoms and co-morbid syndromes associated with this illness render the process of moving forward one of trial and error. The experimental nature of the therapeutic process, full of dead ends and turns is conceptualized in the metaphor of healing as a journey, or long road. As previously mentioned, there is to date no definitive treatment trajectory for FM although it is widely recognized that optimal management of this syndrome is achieved through a combination of pharmacological and non-pharmacological therapies (Rosenzweig and Thomas 2009:235). The onus for managing

this complex chronic illness thus falls squarely on the patient, re-confirming Western cultural ideals of individual responsibility, which Mary clearly expresses:

It's all very much on you and what you can do and you have to create the, you have to basically create your own treatment plan and come up with your own idea about how you're going to live with this. You're not someone with cancer, you're not going to get a whole bunch of community support the same way that certain things trigger that. You very much are in a position where you have to build your own system for interpreting what's happening to you and for believing in how you're going to get better. (Interview January 2012)

The women in this research consistently referred to the cultural credence of legitimate biomedical conditions, of which cancer is one, which provides a motivation for community support and healing. FM as a form of illness which remains contested within biomedicine is fundamentally disjointed from recognition and support at the societal level which leads to feelings of isolation and confirms that, "those who suffer most are those who are unable to do anything about it" (Risor 2010:137). The feelings of alienation and loss spoken of in the previous chapter confirm that for chronic pain sufferers there is no return to a normal cultural performance as the profound pain and fatigue characteristic of FM become a full time occupation (Brodwin 1994: 90). The cultural importance of work in the West as an integral marker of identity for these women is re-confirmed through the reconceptualization of self-care as work in and of itself. The excerpt drawn from an interview with Claire clearly reveals this process:

You know so then once it was diagnosed it also meant that I could read and collect information because to me "knowledge is power." So I was actually glad that it was solved. Like I said I didn't like the answer because I know its chronic but it gave me something I could work on. Being on disability I kind of feel like my job is to get better and to work on dealing with what I have. Like I'm being paid by insurance right and I just think that's what I need to do. I need to read, to go to appointments, to work on dealing with it. So yeah, the day that I was diagnosed I went right away and got two books. I thought, "Ok, here I come." (Interview December 2011)

The disruption in the sufferers' lives due to the telic demand of pain and fatigue which restricts the ability to engage in their respective careers, either through a complete loss of ability to work or the need to adopt a part-time work schedule, is thus discursively negotiated as they creatively reconfigure *disability as work*. The revision of life plans and priorities (the focus of the preceding chapter) coincides with a focus on health seeking, which enables these women to direct their limited energy to the activities they now find meaningful while at the same time justifying their removal from professional expectations (Garro 1994:133).

The pragmatic goal of being free of disruptive symptoms thus becomes an overarching and lifelong goal for individuals with chronic pain conditions and ultimately becomes merged with the normal flow of social life (Brodwin 1994:91). For the majority of the women who participated in this research there was a marked turning point in their experience with FM wherein they realized that allopathic medicine would not be able to provide the overall well-being they are searching for. Karen speaks of this realization as follows:

I think one thing is for me, *you are your own best solution*. You can go to one hundred doctors but they're not going to find a solution for you. I mean if you need medication it's the only place you can get it but as far as you get to see a doctor for what? Five minutes, ten minutes? There's no way that any doctor can learn enough about you and your way of living to help you through it. It's unfortunate but it's probably one of the worst because it isn't easily treated with "Oh go get this test" or "Go do that." You're, if you hired your own [psycho-therapist], and I did, I got some personal counselling that I paid for and those people, since you're paying them by the hour, take the time to ask a lot of questions and guide you into investigating options. But a doctor doesn't have that time. (Interview November 2011).

Implicit in her reference to physicians not being able to understand enough about a patient's way of living is the acknowledgement that healing from FM requires a complete adjustment of one's mode of being-in-the-world. Thus, the emergence of the dys-appearing body which initially calls

for control through learning to pace oneself, simultaneously necessitates a search for the meaning and understanding of one's experience, captured in the term "hermeneutic search."

In the accounts of the women interviewed emerged a strong temporal element of hindsight that builds upon the theme of listening to one's body discussed in the previous chapter. The conferring of a diagnosis of FM thus shifts the line of questioning concerning self and life from what one *has* to what kind of person one *is*; the reasons for why one has developed this particular chronic illness are sought in one's personal being (Bulow 2008:129). The following quote drawn from Mary-Ann reveals this reconsideration of one's life:

It's [FM] made me do what other people I think do normally, which is plan for rest and plan for play, plan for work. That's basically what it's done for me, made me a real person. Because I never factored in myself and because I was a full time worker, I was always having this guilt going home so I ended up divorced, but then I was joint custody so I had the children for a week by myself and he had them for a week. I got to routinize my life and all that stuff, but again I had a demanding mother and other stuff, there was just no me, no time. Now me just kept breaking down and finally breaking down was usually migraines, then finally it converted into FM because I wasn't listening to the migraines. Something tells me, I've been scolding myself like this for a while but it's really accurate, really accurate...So yeah, it's not a surprise that I ended up where I am now. So I see what I did to get here but looking back I do think quite a bit of it would have been preventable with proper education and knowledge. Not just from doctors but on my own part had I taken more time to really know what to do to help manage it. (Interview November 2011)

The reference to a lack of time for oneself in the above excerpt is repeated consistently throughout the accounts and speaks to the discussion in chapter three concerning the cultural expectation of women being primarily open to the needs of others and thus often marginalizing their own lived body. The prolonged emergence of the dys-appearing body in FM has here

resulted in a reinterpretation of one's overall life history. Kleinman speaks to the manifestation of this aspect of chronic illness as follows:

Thus, the chronically ill are somewhat like revisionist historians, refiguring past events in light of recent changes... There is in this persistent re-examination the opportunity for considerable self-knowledge (1989:48).

The overall acknowledgement of the trajectory of their illness coincides with the fundamental tenet of individual responsibility for health in Western culture and is often marked by a sense of regret as in the following statement by Liane: "You know it's a lot of regret obviously I have a lot of regret about things that I could've done or should've done differently." (Interview October 2011).

The diverse array of symptoms that accompany the predominant pain and fatigue of FM, such as depression, anxiety, sleep disturbances and digestive disturbances require constant vigilance as a minute variation may precipitate an immanent change in their overall health, confirming Kleinman's assertion that "change in chronic illness is almost never inconsequential. The chronically ill live at the margin." (1989:44). The necessity of attending to one's body creates a process of tacking back and forth between being absorbed in the daily variations of one's symptoms and being able to metaphorically take a step back and put immediate experience in perspective with life as a whole. Karen speaks of this difficulty as follows:

It's difficult to sometimes look at it that way [whole life picture] when you're down in the dumps though. You're sort of looking through this black... I used to feel that I was out there, life was going on in here somewhere and I'm out there looking in and I couldn't seem to get in with everybody else because I felt I was isolated somehow. And it's very hard to take concrete steps when you feel like that. (Interview November 2011)

The above excerpt vividly speaks of the feeling of being away in experience that is characteristic of the dys-appearing body as one's lived experience becomes disjointed from the everyday world

of others. The telic demand of pain, and the pragmatic goal of being free from disruptive symptoms ultimately necessitates an renewed engagement with the world, clearly reflected in the following statement of Kathleen:

So, you go on just living with these symptoms until sort of like I said the straw that breaks the camel's back and you say I can't live like this anymore. (Interview September 2011).

The Role of Self-Education in Overcoming FM

To live with FM has been found to be a process of adopting changed attitudes while striving to find and maintain balance. This process is often complicated by ineffectual medical advice concerning therapies and treatment due to the recurrently episodic symptoms of FM (Cunningham and Jillings 2006:264). The decision to draw on multiple forms of allopathic and alternative therapies, concomitant with exercise and diet regimes that runs throughout the interviews confirms the necessity of addressing illness as a total experience. As Martha states:

[You need to] change your diet completely, it's your whole body, your whole self I mean. You have to change everything in your life, your diet, your activities and everything. (Interview December 2011)

In addition, the experience of individuals with chronic illnesses has been reported as a constant sequence of activities and actions, which may or may not result in increased health. However, being active is emphasized as it signifies an important commitment to engaging with life and health (Rosir 2010:138). Wendy reasserts this necessity of being involved in activities:

I'm involved in whatever I can be to better myself and I am a lot better than I was. I also attended, it's called a chronic pain management program, it's through the Ottawa hospital, at the general campus in the rehabilitation section. So I participated in that. It was every day for one month and that's where they taught me pacing, you know things like that. A whole bunch of tips

and tricks and strategies really how to deal with my fibromyalgia. And they were awesome really, meditation all kinds of stuff. I think I pretty much jumped on anything that is available and out there for fibromyalgia. I get involved or am still involved.... It's really, really slow. But I am better than I was, no question, thanks to the medication, thanks to my pacing, thanks to the strategies I've been taught, everything that I'm involved with... (Interview November 2011)

The insistence on being actively involved in whatever one can do to improve one's condition speaks once again to the consideration of self care as a career in and of itself. It also confirms the distancing from the everyday world of others as one's activities are forcibly re-orientated around the dys-appearing body (Good 1994:125). The rehabilitation program for individuals living with chronic pain that Wendy speaks of in the above excerpt was an integral component of the search for restored well-being for a majority of the women in this research. The participation in the rehabilitation program can be considered as a form of self-care in that it is a voluntary program, which provides a consolidated source of knowledge that nonetheless requires individual experimentation to determine what methods of symptom management work best for each woman. In addition to providing the women who participated in the program with strategies for learning how to "pace themselves" in their daily activities and manage their symptoms the program was credited with enabling these women with the ability to begin to communicate about their illness. Martha expresses this process as follows:

So, it's a big challenge for someone with fibromyalgia. I mean that even your family cannot understand you. But for me to be in the support group and to be in the rehab program helped me to be able to express myself. Otherwise I didn't know how to express myself. (Interview November 2011)

The absence of outward, visibly manifest symptoms for those living with chronic invisible illnesses, such as FM, often means that their illness experience is delegitimized and relegated to the domain of psychogenic disorders which implies, as previously discussed, the societal

perception of a loss of individual control and intentionality (Ware 1992:353). For these women, the involvement in multiple forms of self-care highlights the need to find the means of understanding one's own corporeal experience of FM before being able to attempt to communicate it to others. In addition to the rehab program, various forms of psychotherapy, but especially behaviour modification therapy, was reported as an important component of their health seeking which enabled some of them to learn to ignore the pain to a certain degree. The women were thus able to re-establish a certain measure of corporeal disappearance characteristic of the ecstatic mode of being-in-the-world. Mary speaks of this experience as follows:

I was in a lot distress because I was in pain a lot of the time and the trouble with pain is that pain is generally a signal that something is very wrong and if you feel like you've been run over by a truck basically from the fibromyalgia and you're aching all the time and feeling terrible and every time you move you're getting these terrible pains and every time you stay still you're getting these terrible pains it's just very anxiety causing because I think pain, when your body is working properly, is a signal that there's something you need to attend to, you know, whereas for me it was like hey this is the new normal, nothing is broken. It's almost like there's been a reset of the system cause I mean I think everyone, any average healthy person still has stuff in their body that you know maybe aches. You have aches and pains here and there and you're just kind of used to them. They're in the background and you just kind of get on with things and that's what I learned to do really as a consequence of working with my psychologist. Whatever it was about the pain that caused me to stress before I've been able to sort of disengage from that and just accept that it's pain. It doesn't mean I'm dying, it doesn't mean my life is over. It's amazing through mindfulness you know I would realize I'd be sitting on a couch, I'd get up, I would have a sharp pain in my knee and think oh god what now? Am I ok? I don't think I'm ok, my life is over, it sucks that I can't work, I'm never going to be normal again and all this because I had a pain in my knee. Now it's just sort of a pain in my knee and that's it. (Interview January 2012)

In her ethnography of a pain clinic, Jean Jackson speaks of a similar process; through biofeedback training, relaxation and imaging therapies focused on the principle "mind over matter" individuals were taught how to use their mind, not to eliminate pain, but to push pain

aside and go beyond the experience (2001:150). The acceptance of pain as part of oneself through integrating the pain into the self thus decreases the power this aversive experience has over one's life. In addition, through dis-engaging from the aversive embodied experience of pain despite its continual presence these women are brought back into the cultural fold so to speak, as they have partially regained the ability to marginalize the lived body characteristic of the ecstatic mode of existence.

There was considerable divergence amongst the women interviewed as to the reliance on physicians' prescriptions of pharmaceuticals as the primary mode of treatment of the symptoms associated with FM. In my opinion, this divergence speaks to the interplay between belief and reality in relation to one's body (Greenhalgh 2001:295). Previous research on chronic pain conditions reveals one of the primary concerns of the use of pharmaceuticals is that of developing a dependency on medication. This is further compounded by the often troublesome side effects that regularly outstrip the relief the medications provide (Jackson 2001:34, Ohman, Soderberg and Lundman 2003:537). Thus, while the women who participated in this research used pharmaceuticals for depression, anxiety, pain and sleep disturbances to varying degrees there was a consensus on the need to create a more holistic approach to their health. As an example, Karen speaks of her approach to managing FM:

Yoga, hot yoga, hot hatha, so a variety of different kinds of yoga and when it gets bad, meditation. I have meditation tapes so I'll do that usually every day and when there is no one else around I will just go do my own thing. I have a little spot in the sunshine that works for me. But other than that it's just sort of pull back a bit. I also have a couple of self help books, books for positive thought which I tend to read to try to get myself thinking more positively. (Interview November 2011)

Thus, in addition to allopathic medicine these women engaged in all manners of alternative and

complimentary therapies ranging from psycho-therapy, yoga, meditation, empowerment through self help books, Tai Chi and Qigong, aquasize classes (water aerobic classes), acupuncture, massage therapy, to special diet plans, dietary supplements and homeopathic treatments amongst a wide variety of other approaches. The recurrent ambiguity surrounding FM reflected in the lack of a coherent clinical system for managing this illness ultimately entails a huge investment of resources and time on the part of individuals with FM. When I asked the women in this research what they had found most helpful in their experience of living with FM there was a common emphasis on knowledge and understanding, exemplified in the following quote from Martha:

With what I passed through the help is not the medication, the help is the education. To educate people to understand themselves...the awareness of what you have. It is the most important thing. Then after you understand yourself then you can even tell the people around you how you are feeling because you know how to express yourself. (Interview November 2011)

The withdrawal from social and work related activities concomitant with the emphasis on pacing oneself and listening to one's body, the focus of chapters three and four, ultimately colludes with the considerable time and energy invested in self education to enable these women not only to manage their symptoms but to learn how to express themselves and ask for assistance. The following excerpt from an interview with Mary provides an interesting commentary on the difficulty of asking for support which speaks to the cultural construction of illness experience:

I've also really tried to just not be embarrassed or ashamed or kind of attach any negative connotations to needing the support. Because I think we get in our own way a lot of the time. We can be too proud. We can feel that we don't deserve assistance. We can be fearful. We can worry about what other people will think about how we have to do something. And so then we don't do it. Well it's sort of incumbent on the person with a disability to speak up and ask for what we need and not assume that everyone else necessarily knows what to do...And it's my own fault for saying tired instead of fatigue, I think people might respond differently. There are definite communication issues. (Interview January 2012)

The Role of the Support Group in the Search for Restored Well-Being

As discussed in the preceding section, the importance of regaining a measure of control over their lives and an increased sense of well-being was achieved through both an emphasis on self education, as well as the search for and use of complementary healthcare therapies. For six of the nine women interviewed an integral part of this whole process was attendance at the monthly meetings of a local FM support group organized by volunteers who themselves live with this syndrome. A portion of this research took place through participation at these monthly support meetings at a local community centre here in Ottawa from October 2011 through to March 2012. These informal support meetings were an hour and a half long and were scheduled during the work-day lunch hour to accommodate the diversity of experience in the severity of FM as some of the members remained employed while others were on disability. The meetings were loosely structured around an agenda of FM related topics with considerable time allotted to discussing individual thoughts and experiences. The importance of sharing one's ongoing story of living with FM discloses the notion that:

Serious illness is a loss of the "destination and map" that had previously guided the ill person's life: ill people have to learn "to think differently". They learn by hearing themselves tell their stories, absorbing other's reactions and experiencing their stories being shared (Frank 1997:1).

The support group provides an avenue of empathic understanding of experience which is often missing from interactions with non-sufferers. In their dealings with others, the difficulty in communicating about pain often coincides with the cultural stereotyping of individuals with FM as archetypical malingerers. In addition, the constant need to decide how to present one's experience of pain is commonly spoken of as demoralizing because the conscious decision to communicate about pain is often times interpreted by others as morally suspect: a circumstance

that contributes to the sense of frustration of explaining one's condition to anyone without a similar experience (Jackson 2001:38).

The inherent unease with communicating about FM, in the initial stages of their illness, therefore stems from the dilemma of what should be concealed and what should be revealed as FM. This makes the syndrome a great example of an illness that remains an "unfamiliar cultural object" (Hilbert 1984 in Bulow 2008:124) as was consistently shown throughout the accounts offered by the women in this research. The role of a community based support group organized by volunteers who themselves live with FM provides individuals with a measure of understanding and a reassurance that they are not alone in their illness experience (Soderberg, Lundman and Norberg: 582).

There was a welcoming, communal atmosphere to the local support group meetings I attended which were facilitated by three organizers. Their role was limited to ensuring that anyone who wanted to voice an opinion or topic was heard with an overall emphasis on positive empowerment and knowledge sharing that reconfirms the role of support groups as stated above. Wendy confirms the importance of support groups organized by sufferers:

I really like our support group that you attended, like it's uplifting and positive and it's not a downer and we share information so I really look forward to going to the support group (Interview November 2011)

The support group provides a means of establishing a common experience that confers a measure of normality on an otherwise misunderstood and disruptive corporeal experience, thereby enabling those who participate to conceive of a manner of accepting their embodied change (Manderson 2011:48). The meetings were typically comprised of eight to fifteen women in the age range of thirty to sixty. There were two or three men who were also members of the

group, however they were absent for three of the five meetings I attended. In addition to providing an informal arena for discussion of FM and health related issues the support group organizers had amassed a small collection of educational materials available for loan by the group members. Included in this collection were take-home sheets explaining FM from a sufferer's perspective, FM from a family member's perspective, clinical literature on the syndrome, a large manual on the process of applying for disability, literature on living with FM, as well as a large clinical manual on common pharmaceuticals prescribed and their anticipated side effects. Topics discussed over the course of the meetings I attended ranged from the emergence of new symptoms, modifications to diet and supplements, medications that had been tried, complications from medications, complementary therapies used, community based exercise programs, and experiences with certain physicians and clinics. This engagement in self education through individual research as well as knowledge sharing in the support group coincides with previous studies of chronic illness, which found considerable action directed towards the illness and symptom management due to a necessity of finding appropriate treatment options (Risor 2010:143). Furthermore, the multi-dimensional approach these women were taking to understanding and healing their disrupted lives echoes previous research into chronic illness according to which:

...the major part [of healing] takes place beyond the context of illness, medicine and clinical encounters, within the realm of social relations, everyday life and existential reflections (Rosir 2010: 147).

A prominent concern that surfaced in all of the support groups meeting I attended was the lack of an integrated system of knowledge of biomedical and support programs for individuals living with chronic pain conditions in Ottawa, which was seen as a severe impediment to improving one's health. Liane speaks of this quite clearly in her interview:

It's been great, it's been really good [the support group] and then the people that I met through the chronic pain management program at the Ottawa hospital...I'd learned a lot of the stuff that they were teaching but it would have been great if someone had delivered me that same kind of package within the first three to six months after diagnosis. Which is when it is needed. But even most doctors in town locally don't even know that the Ottawa hospital offers this chronic pain program. I told my new family doctor about it because it wasn't her that referred me it was my pain doctor. So I'm spreading the word to my other physicians and specialists and that's sort of what your role becomes; do you know about this program? Do you know about this program? And you as the patient have to be the ones educating the doctors. A lot of role reversal but again they don't have the time and I understand that, but still it could be so helpful. There are so many people out there that could have been helped by this and same for me. Wow I could have used this a lot of years ago. But at least I got there so but it took a long, long time and the programs been going on for ten years, this is not a new program; it's been around. (Interview October 2011)

The support group has become for these women an arena for resisting the implicit marginalization of FM both within the biomedical community and society at large through establishing their own network of knowledge about their condition. The generated knowledge is then disseminated both to others with chronic pain as well as back to their various healthcare providers. The diversity of approaches to the management of FM discussed in the meetings thus highlights both the complexity of this syndrome and the current absence of a definitive treatment plan for sufferers. This lack can be said to perpetuate the hermeneutic search on the part of individuals living with this syndrome. Further, through sharing their diversity of experiences and personal approaches to the management of FM these women are able to transcend the normalized, cultural view of "being a Fibromyalgic" through voicing the actual lived experience of FM and creating a common understanding between individual and group experiences that ultimately enables a reconstruction of self (Manderson 2011:49).

Learning to Accept Oneself: the Underpinning of the Hermeneutic Search

Underlying the search for a meaning to and understanding of the lived experience of FM through engaging in self education, complementary and alternative therapies and support group meetings is a quest for the means of reintegrating one's body with one's sense of self. The overarching metaphorical representation of this search as "a journey" or "a long road" necessarily plays on the cultural narrative of stoically continuing in the face of adversity, while simultaneously highlighting the hills and gullies, or hardships, of daily life with a chronic illness. Frank, in his book *The Wounded Storyteller* asserts that "human illness, even when lived as a quest, always returns to mourning" (1997:136). With the onset of illness there arises in the experience of chronic illness a point of disjuncture in their life plans which divides the biographical narrative into a before and an after (Garro 1994:104). Wendy speaks of this feeling of loss and disconnection from life as before FM as follows:

You know I just want to get back to my life but I don't know how I can do that right now because everything is so tiring for me, everything is an effort. I know it's real because I've changed, even my personality has changed, unfortunately, I used to have so much energy. So I don't really have any self-esteem. Or self confidence at all. It's probably at its lowest I'm thinking. (Interview November 2011).

This description of a crisis of the self in chronic illness agrees well with Jackson's observations on the relation between body and self:

An individual with a pain-full body finds that, to a great extent, this body had determined the self he or she has acquired. Although unwanted and rejected, this new self is, like the new body that accompanies it, still one's self (Jackson 2001:149).

There is either implicitly or explicitly the recognition throughout the interviews with the women in this research that the complete re-valuation of their lives initiated by the onset and

eventually prolonged nature of FM ultimately requires an acceptance of a change in self. The following excerpt drawn from an interview with Liane expresses this realization:

The new you, yes. To know that the new you is Ok and it's not any better or worse than the old you. It's just different. Just different. Hopefully better. You know really and eventually it probably will be better. But the pain is a part of who you are. You got to accept that it's not going anywhere and stop chasing the magic pill and stop chasing the magic cure and just stop the chasing. It's important to stop that. To realize that I've got to live with who I am *right now* with these limitations which may or may not get worse and may or may not change from day to day and it's going to hurt. So do things differently. (Interview October 2011)

The emergence of the dys-appearing body initiating a disruption in one's ability to engage in work as before the onset of FM colludes with the restriction in social activities to fundamentally erode one's sense of self on the professional, social and ultimately intimate level. Thus the ontological challenge to the integrity of self presented by the experience of FM comes to fruition in the hermeneutic search. The explicit acknowledgement that the pain is part of oneself and that one needs to learn to live with who one is in that particular moment is the overarching answer these women find on their hermeneutic quest; ultimately, this answer enables them to achieve a kind of reintegration of self and body, however precarious and contested.

Conclusion

This thesis has endeavored to explore how individuals who live with Fibromyalgia, an invisible chronic pain syndrome, communicate about their everyday meaningful embodied experience of this syndrome. The phenomenological perspective enables one to see how the experience of FM as an illness is subtly communicated through a withdrawal from theretofore meaningful activities and relations in these women's lives, rather than being explicitly communicated through words or overt gestures as one would initially expect. While these women, and individuals with chronic pain in general, are given recourse to vivid metaphors to communicate their corporeal experience to non-sufferers this direct form of communication does not predominate in the experiential accounts offered. While the unique contents of illness narratives implicitly speak to the cultural processes at work in the lives of individuals the importance of an anthropological understanding of illness lies in revealing the underlying structure of the illness process, which is defined as follows:

...the manner in which illness is made meaningful, the process of creating meaning and the social situations and psychological reactions that determine and are determined by the meanings. Illness is deeply embedded in the social world, and consequently it is inseparable from the structures and processes that constitute that world...an inquiry into the meanings of illness is a journey into relationships (Kleinman 1989:185).

What has emerged from the commonalities running through the narratives of the women in this research is insight into both the structure and meaning of FM as a particular form of illness. The exploration of the structure of illness experience of FM was here guided by adopting a phenomenological perspective in an attempt to redress the purely materialistic consideration of illness as a set of symptoms dissociated from the individual's life as a whole, characteristic of much of the existent literature on FM. Through inquiring into everyday life with Fibromyalgia

the women who participated in this research were encouraged to present their total experience of living with this illness. At the broadest level the structure of the experience of living with Fibromyalgia is represented by the overarching themes of the three ethnographic chapters of this thesis: falling apart, pacing oneself and the journey. The first of these themes evokes a metaphysical catastrophe of the self as the metaphorical notion of falling apart implies a deviance from the upright posture which in Western culture pre-supposes a fall from social favour and morality inferred from one's loss of corporeal control. This theme thus presents itself as the concrete articulation of the intentional disruption characteristic of the emergence of the dys-appearing body in general. It was expressed by the women in this research in terms of a temporary or permanent loss of the ability to engage in work, conceived of as a primary culturally informed mode of being-in-the-world; a loss that disrupts their self-definition as members of their profession as they are confronted with the label of disabled or "Fibromyalgic."

The second overarching theme emergent in this research, that of "pacing oneself", evokes the experience of measured movement referring to a need to realign oneself due to the uncertainty initiated by corporeal dysfunction. Additionally, the term pacing metaphorically connotes a sensation of impatience, arising from feeling bound in place and time when one wants to progress onward. The phenomenological theme of spatio-temporal constriction was thereby expressed by these women as the experience of being at the will of the dys-appearing body which restricted their engagement in social activities, ultimately lead to a decay of the social self which called for a revaluation of life priorities.

The third theme representative of the structure of experience of FM, "the journey", has marked spatial and temporal elements of a movement towards a renewed commitment to the world and continuance in the face of the adversity posed by FM. Further, the reference to a

journey, alternatively expressed as a long road, calls to mind the acknowledgement of an uncertain end point or destination as FM is inherently a chronic condition. The search for an understanding for and meaning to their lived experience of FM, i.e. the hermeneutic search, manifested itself through approaching their illness as work, or a career, in and of itself. This creative transformation of loss into self-care was described as achieved through self education, reliance on diverse allopathic and alternative therapies as well as, for the majority of women in this research, participation in a local FM support group; all of these elements facilitated an understanding of experience that initiated the process of healing the disjuncture between self and body.

There is thus implicit in the sequence of the metaphors of falling apart, pacing oneself and the journey a marked reflexive progression through experience that discloses the continual and underlying existential commitment to being-in-the-world intrinsic of human existence. Furthermore, these three overarching metaphors are drawn from the collective Western cultural repertoire of representations of experience, thereby providing a structure for both the verbalization and non-verbal expression of illness experience. One notable characteristic in the metaphorical expression of FM is the reliance on auditory and tactile senses to the exclusion of the visual sense normatively given cultural primacy. The necessity of communicating one's corporeal experience of FM through vivid metaphors such as burning pain, electrical shocks, being stabbed with a knife, feeling as if one had consumed one hundred cups of coffee, crawl into a hole and many others discloses the invisibility, aversiveness and unintelligibility of this syndrome to non-sufferers. The meaning of the lived experience of FM therefore emerges in part from the inter-section between conventional metaphors common in Western culture and idiosyncratic metaphors specific to the experience of this particular illness.

The meaning of FM that I propose based on the contents of the interviews and my participant observation in the local support group meetings is that this particular form of illness is the articulation of a tension inherent in our meritocratic culture which praises individuality and hard work yet preaches marginalization of one's embodied and unique self. Mary-Ann, in reflection on her experience with FM, states:

I also call it the disease of having it all...because we were all so active we can't be anymore. I'm sure there is a certain sense to that. (Interview December 2011)

The invisibility of FM in terms of a general lack of outward symptoms enables sufferers to avoid explicit communication of their syndrome and perpetuates the ability to ignore the corporeal dysfunction until a profound disjuncture of self and body occurs. Further, the dys-appearance of the body in FM manifested through a staggering array of symptoms coincides with the ambiguity concerning diagnosis and treatment of this syndrome to fundamentally challenge one's personal phenomenological understanding of the illness. The inherent difficulty in communicating about Fibromyalgia is perhaps representative of the following:

Seriously ill people are wounded not just in body but in voice. They need to become story tellers in order to recover the voices that illness and its treatment often take away. The voice speaks the mind and expresses the spirit, but it is also a physical organ of the body. The mystery of illness stories is their expression of the body: in the silences between words, the tissues speak ...In stories, the teller not only recovers her voice; she becomes a witness to the conditions which rob others of their voices. When any person recovers his voice, many people begin to speak through that story (Frank 1997: xii).

The spatial and temporal distancing from work and social relations characteristic of both the initial onset, and process of learning to manage the symptoms of FM removes individuals from the everyday world giving them the time to understand their lived experience. Through self education and participation in rehabilitation programs and support groups, these women share

their stories, and recover their voice as the above quote asserts, learning in the process to express their needs both within their immediate social circle and their life more generally. Therefore, Fibromyalgia emerges as the ultimate expression of embodied individuality as the immense diversity of illness experience defies categorization and requires a revaluation of life on social, physical and existential levels unique to each person with this syndrome. The suffering that is conveyed through the embodied experience of this invisible chronic pain syndrome is therefore perhaps that of learning to advocate for oneself and to take time for oneself in a culture that demands self marginalization. It is however, a continual process as Liane states:

Again *learning* to communicate, I mean I'm still working on it and you still, you change what you say and how you say it and it gets more refined as the years go by. And then as the new problems go by you have to come up with sort of new speeches. (Interview November 2011)

On a final note, I will return to the question in the introduction of this thesis and offer my current perspective concerning the role of anthropology beyond academia in the lives of those who live with chronic illnesses. In addition to being asked about the role of anthropology in the study of FM and chronic illness more generally I was either subtly or explicitly encouraged by the participants in this research to forsake my current career path in anthropology and pursue a career in medicine; as one woman at the support group jokingly said they would all willingly become my patients. I do not take this as a personal commentary on the work I have completed here but see their reaction instead as a variation on a more widespread cultural commentary on two things. The first is the existing structural constraints in the medical system which do not generally allow practitioners to allot adequate time to fully understand the complexity of chronic illnesses thus creating a "moral lacuna" (Kleinman 1989:29) in their relationships with patients that distances them from their commitment to healing through the empathic sharing of human suffering. Similar concerns were echoed in both the clinical conference I attended during this

research and throughout the interviews with the participants. Secondly, the comment reveals the everyday perceived incommensurability at the societal level between social science research and tangible interventions in the lives of individuals who live with chronic conditions. Illnesses such as FM assault the bodily integrity of sufferers who often times report feeling that their very existence is at stake (Raheim and Holland 2006). As I currently see it, the role of anthropology in the lives of those who live with chronic illnesses is not all that different from the underlying role of a primary care physician in that both offer the possibility of what has been termed “empathic witnessing” (Kleinman 1989:54): the commitment to be with the ill individual as they author their respective illness narrative and thus bring their phenomenologically real self into being. While this role is modest in comparison to the biomedical project it is important as it provides a counter balance to the proliferation of studies focused solely on the material body. Thus the role of anthropology beyond academia is perhaps not too dissimilar to the lesson inherent in FM itself: learning to listen and to communicate to a broader audience:

If there is something I could hope would be accomplished through the use of medical anthropology in our case would be to somehow communicate to the medical profession, to the government, to the people who have the power to make things easier. You know just the message that I don't think I've ever met anyone at the support group meeting or anywhere else who is a malingerer, who is lazy or who is trying to take advantage of the system. (Interview with Mary, January 2012).

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